Creating a Cancer Survivorship Program

Insights from Successful Programs:

Connecticut Challenge Survivorship Clinic
at Yale Cancer Center

HEROS Clinic at Yale University

Perini Family Survivors' Center and LAF Survivorship Clinic
at Dana Farber Cancer Institute

Memorial Sloan-Kettering Cancer Center

Produced by the Connecticut Challenge

Edited by **Kenneth Miller, M.D.**
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- **Scott Capozza, PT,** Connecticut Challenge Survivorship Clinic at Yale Cancer Center
- **Lina Chase, LCSW,** Connecticut Challenge Survivorship Clinic at Yale Cancer Center
- **Maura Harrigan, RD,** Connecticut Challenge Survivorship Clinic at Yale Cancer Center
- **Thomas Quinn, R.N., CNS,** Connecticut Challenge Survivorship Clinic at Yale Cancer Center

Yale Cancer Center continues to be a great partner with the Connecticut Challenge in supporting our programs and helping us enable other hospitals and providers across the state to access best practices and information about cancer survivorship programs. This would not be possible without the assistance and support of its director, Dr. Richard Edelson, whose foresight has lead us to where we are today. Contributing to our ongoing evolution and leading our work in childhood cancer survivorship is Dr. Nina Kadan-Lottick. Dr. Kadan-Lottick passionately directs the HEROS Clinic at the Yale Cancer Center from which we continue to gain inspiration for our programs. In addition, we are privileged to work with some of the top researchers in cancer survivorship within the fields of nutrition and physical activity. Dr. Susan Mayne and Dr. Melinda Irwin at the Yale School of Public health guide our practice philosophies in nutrition and physical activity respectively, backing them with unique insights and solid data.

We welcome the contributions from other faculty and staff at several of the leading Universities and Cancer Centers across America including the National

Cancer Institute, MD Anderson Cancer Center, Dana Farber Cancer Institute, Memorial Sloan Kettering Cancer Center, The Moffitt Cancer Center, Gallaudet University and the Wellness Community. The individual contributors, listed alphabetically, are as follows:

- **Richard Boyajian, N.P., R.N.,** Dana Farber Cancer Institute
- **Mitch Golant, PhD,** Vice President, The Wellness Community
- **Melinda L. Irwin, PhD, MPH,** Associate Professor, Yale School of Public Health
- **Paul Jacobsen PhD,** Moffitt Cancer Center
- **Heather Jim, PhD,** Moffitt Cancer Center
- **Nina Kadan-Lottick, MD, MSPH,** Director, HEROS Clinic, Yale University
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- **Susan Taylor Mayne, PhD, F.A.C.E.,** Professor, Yale School of Public Heath
- **Andrea Ng, MD, MPH,** Associate Professor of Radiation Oncology, Harvard Medical School
- **Leslie R. Schover, PhD,** MD Anderson Cancer Center
- **Usha Thakrar, MPP,** Program Administrator, Perini Center, Dana-Farber Cancer Institute
- **Lois B. Travis, MD, ScD,** National Cancer Institute, NIH, DHHS

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We also wish to thank Bob Mazzone who contributed his time coordinating the overall project.

Thanks to everyone for Joining the Challenge!

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Forward

Dear Friends,

Not often do we get a chance to engage with so many professionals who share our goals of providing better care for cancer survivors. It is our honor to have you join us and by reading this document we hope that you can learn more about the importance of post treatment cancer care and how to establish a program within your organization.

We want to thank Dr. Ken Miller for all he has done to help shape cancer survivor care and guide our provision of services at the Connecticut Challenge Survivorship Clinic at Yale Cancer Center. Ken has taken our vision of a comprehensive clinic, expanded on it and made it real. For that, we are incredibly grateful. We wish Ken all the best as he moves on to direct survivorship programs at Dana Farber.

Along the way, we all learned a lot about how to administer services to cancer survivors. We have spoken with hundreds of patients and have grown to appreciate all of the health and life issues they face following their disease and treatments. This growing population of 120,000 in the state needs the help of their local medical professionals to regain their health and lead the lives that they are entitled.

We support your efforts to improve the quality of care for cancer survivors and hope you find this document useful in developing a comprehensive program for your patients. Please feel free to contact us, share your experiences or get involved in our programs to advance survivorship across Connecticut.

Thanks for Joining the Challenge!

Sincerely,

Jeffrey Keith	**John Ragland Jr.**	**Bob Mazzone**
Co-Founder	Co-Founder	Executive Director

About the Connecticut Challenge

The Connecticut Challenge was founded in 2005 to serve the unique health needs of cancer survivors in the state of Connecticut. The two founders, Jeff Keith and John Ragland, initially envisioned the creation of a clinic where comprehensive health and wellness services would be administered beyond what the oncologists and primary care physicians typically incorporate into their practices. They chose to partner with the Yale Cancer Center, with a proposal to jointly develop a survivorship clinic, which the Connecticut Challenge would help to subsidize with the proceeds from a fundraising bike ride.

Just a vision in 2005, the Connecticut Challenge Survivorship Clinic at Yale Cancer Center became a reality in 2006, opening its doors each week to welcome cancer survivors. The concept of a survivorship clinic was new and these people had little idea what to expect from their visit to the clinic, but their motivations were strikingly similar. They had come through their diagnosis and treatment under the careful, watchful eye of skilled doctors and nurses, but now, in the post-treatment phase, they were left with little information about what to expect next and trying to piece together their own care plan.

> "After you're done with treatment and your operation, people ask, 'so, why aren't you back to normal?' Well, the people at the clinic are telling me, 'well, you're not.' Coming to this place is helping me to go on in a 'cancer normal' life. They are telling me what to expect, my limitations, how I can improve myself and how I can become a healthy person again."
>
> –Audrey, Eastchester, NY

Shortly after the adult clinic opened, the CT Challenge also started supporting the state's first clinic for survivors of childhood cancers, appropriately named the HEROS Clinic (Health, Education, Research, Outcomes, Survivors), also at Yale Cancer Center.

Much of cancer survivorship care is about empowering people to take control of their lives and their health back from a horrible disease. These clinics have helped hundreds of cancer survivors to understand the many challenges they face or may face in their "new normal" life as a cancer survivor and chart a course forward as a healthy person.

"The HEROS Clinic was a light in the dark. Once they helped me understand my risks – and more importantly, what I could do to mitigate them – I felt empowered. It was such a relief to finally have someplace to turn with my questions."

– **Kelly, Naugatuck, CT**

But "hundreds" does not begin to reach the number of survivors who could benefit from access to comprehensive survivorship care. The number of survivors in Connecticut is about 120,000!

Moving forward, to address the needs of this vastly greater audience, the Connecticut Challenge intends to expand its scope to work in partnership with hospitals and community organizations across the state. We hope to draw on their desire to support their patients through every stage of the cancer continuum: diagnosis, treatment AND survivorship. Our intention is to create a survivorship network – the *Connecticut Challenge Survivorship Network*. This network will state clearly to cancer survivors that, no matter where they live, they have easy access to a comprehensive survivorship program through their local hospital or community organization that is based on the tried and tested model in place at Connecticut Challenge Survivorship Clinic at Yale Cancer Center and other hospitals around the state. Over time, with input from all members, Connecticut's survivorship network will continue to raise the standard of care for cancer survivors.

Our mission is to ensure that all survivors are aware of the potential long term effects of their disease and treatments and that they have the proper local resources available. In addition to the Connecticut Challenge Survivorship Network, the Connecticut Challenge will be providing patient education, financing survivorship research and hosting awareness building events.

The signature charity bike ride - the Connecticut Challenge - has funded all of our programs and research to date. It is entering its 5th anniversary year having hosted over 1,400 cyclists of all ages and skill levels who have raised almost $2 million. This extraordinary event, which is scheduled for the last Saturday in July, brings together people of passion, commitment and energy. We welcome you to join us. With your help, this ride will continue to be the fundraising engine that drives the Connecticut Challenge programs and the Connecticut Challenge Survivorship Network. We are excited by the potential of the ride and the future survivorship programs and services it will make possible.

"People diagnosed with cancer come in all ages, shapes, colors, from different ethnic, religious, and socioeconomic backgrounds."

Kenneth Miller, MD

Introduction to Cancer Survivorship

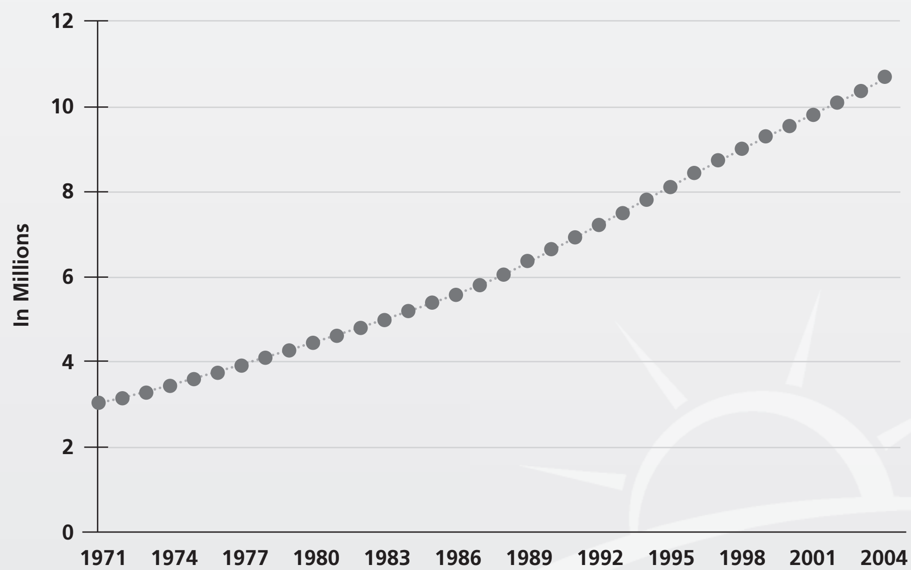
(Adapted from *Medical and Psychosocial Care of the Cancer Survivor,* Jones and Bartlett, *In Press*)

Kenneth Miller, MD, Assistant Professor, Harvard Medical School

The definition of "cancer survivor" is a topic of discussion and debate. According to the definition developed by the National Coalition for Cancer Survivorship in 1984 and accepted by the National Cancer Institute, an individual, his or her family and caregivers become cancer survivors from the moment of a cancer diagnosis and remain one for as long as he or she lives.

Many embrace this definition, while others are uncomfortable with it. Some people believe that the term "cancer survivor" should be reserved for people who are in a long-term remission or are cured, that accepting this title early risks being overly confident of one's health. Others do not adopt the term "survivor" because, historically, it has been linked with the Holocaust or with natural disasters. Other titles have been used for cancer survivors, including cancer "veterans," "victors," and "heroes." When President Nixon signed the Cancer Act in 1971, it is estimated that there were approximately 3 million cancer survivors in the United States. Today, that number is close to 12 million and by the year 2020 there will be about 20 million men, women, and children.

Figure 1 **Estimated Number of Cancer Survivors in the U.S. (1971 - 2004)**



Data source: Ries LAG, Melbert D, Krapcho M, Mariotto A, Miller BA, Feuer EJ, Clegg L, Horner MJ, Howlader N, Eisner MP, Reichman M, Edwards BK (eds). SEER Cancer Statistics Review, 1975-2004, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2004/, based on November 2006 SEER data submission, posted to the SEER web site, 2007.

The term "cancer survivorship" describes a process rather than a person. The process of survivorship starts at the time of diagnosis and then changes over time, establishing a connection between the decisions that individuals with cancer face initially with those they may face five, ten, or twenty years later.

People diagnosed with cancer come in all ages, shapes, colors, from different ethnic, religious, and socioeconomic backgrounds. Similarly, they have different diagnoses and treatment regimes and outcomes. For this reason, it is difficult to define a specific path of cancer survivorship. For cancer survivors, there may be phases of the experiences that are related to the cancer, some to normal aging, and some to the interaction of both.

The journey that cancer survivors make is individual, intense, and an important one for clinicians to understand from a medical, psychosocial, and epidemiologic perspective. Medical treatment for some cancers may be relatively brief and "minor," such as a wide lumpectomy for a minute focus of ductal carcinoma in situ, not followed by radiation, chemotherapy, or hormonal therapy in an 85 year-old woman. Alternatively, a 45-year-old woman might undergo neoadjuvant chemotherapy for treatment of breast cancer followed by surgery, radiation therapy, and then hormonal therapy. Yet another patient may be treated for acute leukemia before undergoing an allogeneic bone marrow transplant.

Providing medical care for cancer survivors is complex by virtue of the diversity of sex, age, diagnoses, and treatments. Many cancer survivors do not experience long-term consequences of treatment, but on the other hand, there are survivors of Hodgkin disease who, after radiation and chemotherapy, are at risk of a myriad of problems, including damage to coronary, valvular, and conduction systems as well as pericardial types of heart disease, pulmonary fibrosis, hypothyroidism, breast cancer, and secondary leukemia.

An understanding of the psychosocial issues of cancer survivorship is also important for clinicians. The fear of recurrence is a major issue and may be inversely proportional to the actual risk. A woman who has a small, noninvasive breast cancer may feel far more at risk of recurrence than a similar woman who has a large invasive cancer with multiple positive lymph nodes. Multiple other issues include depression, anxiety, change in family structure and dynamics, and problems related to sexuality and intimacy. Cancer survivorship affects children of cancer survivors, other family members, and caregivers in ways that are not well understood, but their experiences are important both to the patient and also later during their own lifetime. Some problems that may follow a cancer diagnosis include exacerbation of already existing financial or marital distress and divorce. Children of cancer survivors may also manifest their own stress reactions in expected and unexpected ways. A cancer diagnosis has a "ripple effect" on an entire community in positive as well as negative ways.

"Over the last 20 months I have had to deal with many challenges but my diagnosis and treatment has opened many new doors for me and in many ways it has been a new beginning for me and my family. Cancer is not an individual disease as it affects all of those around you."

– Pat Sclafani / Marlborough, CT

Cancer survivorship is not just a personal, but also a public health issue. If every oncologist in practice were to continue to frequently see the growing number of new patients each year who fortunately are living to be long-term survivors, they would eventually have less time to see patients who present with a new cancer diagnosis. The health care system needs to gradually adopt a strategy to transition some of their care back to primary care providers who also are adept at providing care for their routine health care needs and the special issues related to aging. In this regard, however, it should be noted that 15% to 20% of the patients who are diagnosed with cancer any year are experiencing this as a second or greater malignancy. Screening for second malignancies needs to be a priority of a survivor's care based on normal cancer screening guidelines, but also reflecting the special needs of cancer survivors, including genetic risks, increased risks of certain cancers related to the primary tumor, as well as the risk of second malignancies related to their cancer therapy.

Cancer survivorship may also be a "teachable moment," meaning that cancer survivors can change health-related behaviors to reduce their risk of developing another cancer or cardiac disease. Smoking cessation, better nutrition, and increased physical activity are important goals for everyone, but potentially even more so for cancer survivors. In addition, ongoing screening for recurrence, but also for the development of other common cancer is a priority and includes breast, colon, prostate, and cervical cancer screening. Hence, clinicians have an opportunity to promote good health.

Fortunately, there are a growing number of cancer survivors. The need to respond effectively to the problems and challenges they face will continue to be a growing challenge to health care providers.

Seasons of Survivorship

(Adapted from Miller, KD; *The Cancer Journal*. 2008, 14:6:369-374)
Kenneth Miller, MD, Assistant Professor, Harvard Medical School

In 1985, Dr. Fitzhugh Mullan published an often cited article, "Seasons of Survival: Reflections of a Physician with Cancer" in the *New England Journal of Medicine*. Dr. Mullan was diagnosed with a mediastinal seminoma, which is a rare tumor that developed in his chest. He wrote, "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 the elation at the birth of a daughter in the midst of treatment. It was the anxiety of my monthly chest x-rays. It was survival, an absolutely predictable, but ill-defined condition that all cancer patients pass through as they struggle with their illness."

Dr. Mullan defined three seasons of survival. The first was **"Acute Survival":** A medical stage including the time of diagnosis and then the initial therapy. The second was **"Extended Survival":** A time of watchful waiting with celebration, uncertainty, and transition. Finally, the third was **"Permanent Survival":** A time when a gradual sense of confidence develops when the risk of recurrence is low and that the chance of long-term survival is great. (Figure below)

Figure 2 **Seasons of Survival *New England Journal of Medicine* (1986)**

Acute Survivorship	Extended Survivorship	Permanent Survivorship
■ Initial diagnosis ■ Testing, staging ■ Treatment	■ Recovery from initial treatment ■ Watchful waiting ■ Surveillance with medical testing ■ Recovery, coping, fear	■ Less focus on cancer ■ Returned sense of permanence ■ Coping with late and long-term medical, emotional, social, and other "fall-out."

During previous decades when people diagnosed with cancer were not likely to live beyond the diagnosis, the long-term toxicities associated with cancer treatment may not have been relevant, recognized, or treated. Now however, with a large and growing number of cancer survivors, short and long-term sequelae of treatment have been identified in essentially all organ systems. As cancer survivors are living longer, new problems may be identified that represent the interaction of time, age, and previous treatment.

The basic concept of the existence of different "seasons of survival" defined by Dr. Fitzhugh Mullan has not changed, but the seasons have changed in some subtle ways. There is a larger group of cancer survivors who are living with advanced cancer for long periods of time and another group of survivors who are in a remission that is dependent upon the use of a targeted agent such as Imatinib for patients with chronic myelogenous leukemia. In addition, permanent survival defines a large and heterogeneous group of survivors; some who have moved beyond cancer and are healthy, some who are living with the "fall-out" of the cancer experience, including consequences involving their health, sexuality, career, and insurability, and some who reenter the system year later with a second cancer that is related to or unrelated to their previous cancer and its treatment.

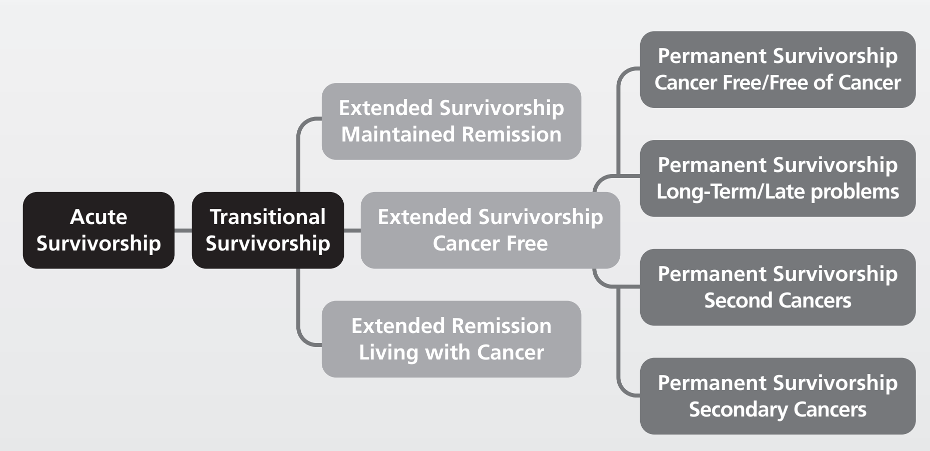
We propose a modified model of the "Seasons of Survivorship" incorporating what has been learned about cancer survivorship during the past twenty years. (Figure 3). It is essential to note that the actual survivorship trajectory for individual cancer survivors is quite variable. For some cancer survivors, the acuteness of the diagnosis and the fear of recurrence may be acute and severe five years later, while for others the transition from acute to permanent survivorship may be quick and natural for reasons that are not yet well understood.

Revised Seasons of Survivorship: 2008

Acute Survivorship

This medical stage is dominated by testing and treatment and is fundamentally no different than it was in the 1980s. The types of therapy and their effectiveness has increased, targeted therapies are now available, some of the side effects of treatment have been mitigated by supportive care advances, and some types of therapy are of shorter duration now than in the 1980s. Nonetheless, cancer survivors still experience that chilling sensation of learning that they have cancer and are faced with the realization of their own mortality.

Figure 3 Seasons of Survivorship (2008)



Transitional Survivorship

The initial phase of diagnosis and treatment has ended and this phase of transitional survivorship may be quite heterogeneous. Cancer survivors may be entering a period of "watchful waiting," or perhaps they will receive some type of maintenance therapy. This is the phase when the medical team is less involved and relief and celebration may be mixed with feelings of isolation and depression.

Extended Survivorship

Many patients are in remission and are not receiving any ongoing maintenance therapy (Group 1). There is another growing group of individuals in this phase of extended survivorship who are living with no evidence of disease, because of ongoing treatment with targeted therapy, such as imitanib in patients with a gastrointestinal stromal tumors (GIST), women with metastatic breast cancer receiving trastuzumab, or survivors with non-small cell lung cancer taking erlotinib (Group 2). The experience of this group of patients who have obtained a remission that is dependant on ongoing treatment is likely to be different than for survivors who are not receiving ongoing therapy. Finally, there are a group of cancer survivors in extended survivorship who are treated and are living with advanced cancer that is not in remission, but rather is a chronic disease (Group 3).

Permanent Survival

There is typically no one moment of cure, but rather a gradual sense or confidence that the risk of recurrence is low and that the chance of long-term survival is great. Some of the immediate and pervasive sense of impermanence lessens and is replaced by more focus on the normal activities of life and the here and now of the everyday. We propose that there are four subgroups. Some are "cancer free and free of cancer," others are "cancer free, but not free of cancer," either physically or emotionally, some reenter the acute phase of survivorship with a secondary cancer related to previous therapy, and others develop a second and unrelated cancer.

"It was after a bike ride with my wife and children that I noticed I was unusually winded and unable to keep up with my family. This was the impetus that prompted me to get a physical, the very one that diagnosed me ultimately with colon cancer."

–**Peter Cutler / Fairfield, CT**

Implications of the Seasons of Survivorship

Twenty-two years have passed since the founding of the NCCS, the new definition of cancer survivors and cancer survivorship, and the landmark paper by Dr. Mullans. The chance of living beyond acute cancer survivorship has increased as has the total number of "permanent survivors." The needs of cancer survivors during each of the "seasons of survivorship" should be the topic of ongoing interest and research in order to improve their quality of life from the moment of diagnosis and then for the rest of their life. As medical advances help to add years of life for cancer survivors, it is equally important to help ensure the quality of those years.

"Developing a comprehensive survivorship program that includes medical psychosocial and supportive care components is challenging and resource-intensive."

Usha Thakrar, MPP

Survivorship Care: Getting Started

Usha Thakrar, MPP, Program Administrator
Perini Center, Dana-Farber Cancer Institute

As the population of cancer survivors continues to grow, the need for comprehensive survivorship care has become more apparent. Cancer care institutions of all sizes face the challenge of setting up appropriate programs and maximizing resources to provide appropriate service to this population. These challenges beg the question – what are the important components in setting up a survivorship program?

Critical Factors of Success

Before addressing any of the "nuts and bolts" of developing a program and delivering survivorship care, it is important to understand several key factors of success.

- There are as many definitions of "cancer survivor" as there are shades of blue. The survivorship needs of patients just completing therapy are very different than those of long-term survivors. **Defining the target population is key.**

- **No survivorship program is going to thrive unless it has both institutional and clinical staff buy-in.** There are many models for caring for these patients going forward, but all of them involve a commitment from their treating oncologist.
- **Supportive care is as important as clinical care.** While not all cancer survivors suffer late-effects, most want information about their survivorship and the opportunity to meet other survivors. Educational and support programs can be as successful and as necessary as clinical care.

Staffing

The staffing needs fall into two major categories – clinical and administrative. Regardless of the clinical model of the program, certain administrative staffing is necessary. Caring for cancer survivors requires complex, multi-disciplinary care and strong communication among patients, survivorship providers, oncologists and primary care. It is critical that any program include a staff member who can schedule patient appointments, ancillary visits and ensure that survivorship documentation (treatment summaries and care plans) are distributed appropriately. In addition, depending on volume, this person can be utilized to generate treatment summary documentation.

Unless one has the luxury of having a free-standing survivorship program, a critical piece of success is integration with existing clinical operations. This includes utilizing scheduling systems, electronic medical records, laboratory ordering, billing, etc. Depending on the size of the program, the operations role can be combined with other critical administrative roles including fiscal management, personnel management and program development.

Clinical staffing depends entirely on the clinical model of care. Regardless of which model is used, developing a survivorship program requires strong clinical leadership. While a number of models exist, they are essentially variations on either a centralized or de-centralized approach.

The centralized approach consolidates multi-disciplinary clinical services in one physical location. Clinical staff includes nurse practitioners, psychosocial providers and subspecialty providers such as endocrinologists, cardiologists, nutritionists, etc. Depending on the volume, most clinical staff is likely to be part-time (either shared with other programs or as contract employees). In addition to providing clinical services, all staff is involved in developing educational materials and programming for patients and families.

The de-centralized approach develops “mini” survivorship clinics within disease centers. Services are spread across the institution and therefore so is staff. This model generally uses pieces of nurse practitioners and psychosocial staff within disease centers rather than having individual dedicated staff. This approach generally refers patients to sub-specialists as appropriate. Depending on the level of disease center commitment, this model can be more fiscally sustainable as it leverages existing resources.

Fiscal Issues

As with any clinical program, the single largest cost is the staff. Regardless of which model is chosen, there will be fixed costs of clinical and administrative staff, not all of which can be billed to insurance. Annual visits to a survivorship clinic are reimbursed by most major insurers as are most screening tests. In general, most visits can be billed between Levels 3 and 5 using a V-code (History of Cancer). One significant difference between survivorship care and oncology treatment is the potential revenue sources. All oncology care has high staffing costs, however on-treatment care can off-set those costs with revenues from infusion services and other treatment-related services. Revenue for clinical survivorship care is limited to reimbursement for patient visits. Depending on the structure of the institution, there may be additional revenue realized from billing for ancillary services (e.g. scans, mammograms, subspecialty visits, etc). In general, survivorship programs are not self-sustaining and must rely on other sources of funding. Historically, philanthropy has been the single largest source of support for developing survivorship programs. As the need for this type of care becomes more apparent, some cancer centers are devoting institutional resources to these efforts. However, anyone involved in the early stages of building a program must include plans for fundraising.

Typical Patient Flow – Centralized model

Patients can be referred through a variety of sources (PCP, oncologist, self). Once referred, patients call the clinic facilitator to schedule a visit and are scheduled to see a nurse practitioner and a psychosocial provider. Patients are asked to send all medical records pertaining to their treatment in advance of their visit. If these records are received in time prior to the visit, the NP reviews the records and may schedule additional testing in conjunction with the visit.

Patients generally see the NP, the psychosocial and other specialty providers for an hour each. After the visit, the nurse practitioner completes the treatment summary and care plan documents which are mailed to the patient and his/her PCP within a week of the visit. If the follow up plan includes diagnostic tests or ancillary visits, the facilitator assists in scheduling.

Final Thoughts

Developing a comprehensive survivorship program that includes medical psychosocial and supportive care components is challenging and resource-intensive. As the field moves forward with the development of standards of care for this population, survivorship programs will need to tailor services accordingly. Those programs that are created with a solid operational and fiscal foundation and are well integrated into their institution, will be best positioned to care for these patients long-term.

The End of Treatment Summary and Short-Term/Transition Care Plan

Richard Boyajian, N.P., R.N., Dana Farber Cancer Institute

Richard Boyajian

The creation of a cancer treatment summary has come to the forefront of oncology care primarily due to the Institute of Medicine's (IOM) report "From Cancer Patient to Cancer Survivor: Lost in Transition." The detailed IOM report published in 2005, made many recommendations to improve cancer care. One of the main recommendations was the creation of a treatment summary and care plan that would document the treatments received, any complications, possible long-term effects that start during treatment, as well potential late effects. Cancer specialists in the fields of radiation and surgery provide summary documentation in the form of pathology/operative reports and radiation summaries. Medical oncology presents challenges because the treatment often spans many months and visits, and does not typically have clearly defined beginning and endpoints. The treatment summary is intended as a strategy to improve the quality of cancer care as detailed in figure 4. There are multiple, important times when cancer survivors benefit from this opportunity to reflect back on their past treatment, their present health, and their future wellness.

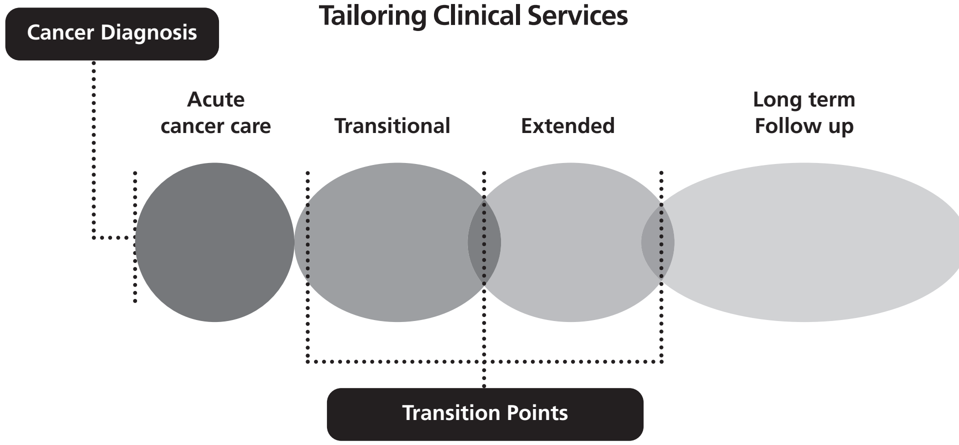


Figure 4 Goals of Oncology Treatment Summary

Adoption of a Treatment Summary could improve 3 interrelated aspects of cancer care delivery:

1) **Care Coordination:** between providers
2) **Communication:** between patients and providers
3) **Efficiency:** document tracking, record keeping for patients, providers, systems, and research

Care Coordination is important because:

- Better survival means more patients transition back to non-oncology health care providers
- Treatment is increasingly complex and teams often include many sub-specialty members
- Society is increasingly mobile and patients transition across practice sites

Communication is important because:

- It is a pre-requisite for shared decision-making
- More complex treatments and preference-sensitive options are now commonplace.
- Patients desire it.

Efficiency is important because:

- It limits time spent reviewing/obtaining/providing/ medical records.

continued on next page >

> ***Figure 4** continued from previous page*

- It facilitates tracking of processes and outcomes of care for quality improvement initiatives.
- It facilitates document storage, retrieval, copying, and transmission.
- It facilitates tracking of care for public health and research data collection.

Key for source information

IC	Initial consult notes from a new provider
PCP	Visit notes from PCP often contain a problem list related to past medical history
EMR	Electronic medical records system have sections dedicated to past medical histories
OVN	Routine Oncology visit notes should also contain this information
OR	Operative (biopsy) reports contain this information
PR	Pathology reports usually contain detailed information
DC	Hospital discharge notes can also contain this information
IR	Radiologic imaging reports (CT, MRIs, mammogram and PET scans)
CFS	Chemotherapy flow sheets may have the treating institution
ROC	Radiation oncology completion notes
RVN	Routine radiation oncology visit notes

The components of a treatment summary are the catalyst to developing a care plan that addresses the holistic needs of every survivor. There are many versions of treatment summaries available and while they differ somewhat, we feel the example used in this document contained the basic elements of all treatment summaries. These include:

Basic Demographics of the Patient (IC, PCP, EMR)

The type of information we talk about here should be readily available in a number of places in the patient's medical record.

Institution Where Treated and Medical Record Number

While it is obvious that the medical record number of your institution should be included in this document, consider providing a place to list the medical record number of each treating institution. This should allow easier access to important documents that may be needed in the future.

Significant Past Medical History
Past medical history is important because it will also influence health care decisions.

Date of Diagnosis (IC, OR, PR)
The date of diagnosis is important because it helps to tell the survivor's story in a certain order. It is important to note that the exact date is not going to make a significant difference in the care of survivors.

Age at Diagnosis
Please refer to the date of diagnosis section. The very same documents will also identify age at diagnosis. The age at diagnosis is important because all risks are not the same for people of different age groups.

See the below example of the importance of the age at diagnosis:

1. *The risk of breast cancer after treatment for Hodgkin's lymphoma is significantly higher 15 years or more after radiation and for women treated before age 30. Long-term surveillance strategies are indicated for women at risk.*
2. *Premature menopause following cancer therapy is dependent on actual treatment and age at treatment. Older age is associated with a greater likelihood of ovarian failure.*

Type of Malignancy (IC, OVN, OR, PR, DC)
This is usually quite obvious but does need to be verified. Often times it is worth double checking by comparing the documents that may contain this information. We would suggest starting with consult/visit notes, discharge summaries, operative and pathology reports dated around the time of initial diagnosis.

Primary Sites(s) of Disease (IC, OR,PR, IR, DC)
The primary site of disease refers to where in the patient's body the cancer was found to have started at the time of their cancer diagnosis. Some cancers such as Lymphoma can have multiple primary sites of disease; where as lung cancer can be in multiple places in the body, but started in one of the lungs. We would suggest starting with the initial consult notes. Consult notes often have the most complete information.

Occurrence-Type
Unfortunately, patients can have multiple occurrences of their malignancy. Patients can also have more than one type of cancer, therefore it is important to list the occurrence type of each cancer a patient has had. See table 1 for the types of occurrences.

Table 1 Cancer Occurrences by Type

Primary	The first occurrence of a specific type of cancer. There can be more than one primary cancer per patient. **Example: The patient may have a diagnosis of prostate cancer and also have a past history of non-Hodgkin's lymphoma, both are separate primary cancers.**
Refractory	A specific cancer did not respond to the treatment. Typically, this would signify a change in the treatment, stopping one treatment and starting a different type. **Example: The patient is being treated for lymphoma and started on first line chemotherapy, but their lymphoma did not go into remission as a result of this chemotherapy. The lymphoma would be regarded as refractory to this treatment and they would need additional therapy.**
Relapsed	A specific cancer was in remission from primary treatment, but unfortunately has returned for the first time. **Example: The patient is being treated for lymphoma and started on first line chemotherapy. The lymphoma goes away completely and they are in remission for a period of time, but then the lymphoma returns. This would be classified as relapsed and they would need a second line therapy to treat it.**
Second relapse	A specific cancer was in remission from the second treatment, but unfortunately has returned for the second time. **Example: The patient was treated for lymphoma with first line chemotherapy. The lymphoma goes away completely and they were in remission for a period of time but then the lymphoma returns. The patient was treated for relapsed lymphoma and started on second line chemotherapy. The lymphoma goes away completely and they were in a second remission for a period of time, but then the lymphoma returns a second time. This would be classified as a second relapsed and they would need a third line therapy to treat it.**
Third relapse	A specific cancer was in remission from the third treatment, but unfortunately has returned for the third time. **Example: The patient was being treated for lymphoma with first line chemotherapy. The lymphoma went away completely and they were in remission for a period of time but then the lymphoma returns. The patient then was treated for relapsed lymphoma with second line chemotherapy. The lymphoma goes away completely and they were in a second remis-**

continued on next page >

	sion for a period of time but then the lymphoma returns a third time. The patient was treated for a second relapse of lymphoma and started on third line chemotherapy. The lymphoma goes away completely and they were in a third remission for a period of time, but then the lymphoma returns. This would be classified as a third relapsed and they would need a fourth line therapy to treat it.
Secondary	This occurrence of a specific cancer is related to their prior cancer therapy. **Example: A female patient developing breast cancer as a direct result of chest radiation she received 15 years earlier for Hodgkin's lymphoma.**

Metastatic Site(s) of Disease

Please refer to the primary site of disease because the very same documents will also identify metastatic sites of disease.

See the below example of both primary and metastatic sites taken from an initial consult note:

> *Patient X felt a bump on her neck while at college and didn't do anything until she went home for Thanksgiving vacation. While at home she experiences itching and a cough and her mother makes her see the PCP because of her history of asthma. Her PCP notes cervical adenopathy and does **CXR which shows mediastinal mass. Biopsy** of a **cervical node** shows nodular sclerosing **Hodgkin's lymphoma.** A staging **PET /CT scan** showed **disease involvement** in the **retroperitoneal and spleen. Hodgkin's lymphoma** was pathologically confirmed on the **staging laparotomy with splenectomy.** A Bone marrow biopsy was done that showed no sign of Hodgkin's lymphoma involvement.*

In this one example from a consult note, we see primary sites of disease (mediastinum, cervical and retroperitoneal involvement). We can see metastatic sites of disease in the spleen, but not in the bone marrow.

Stage of MALIGNANCY (IC, OVN, OR, PR)

Staging is the process of finding out how much cancer there is in a patient's body and where it is located. It is not important for a treatment summary to know how to stage each type of cancer.

Assembling the End of Treatment Summary: What patients, PCPs, and Oncologists want to know.
Several studies have shown that patients often do not accurately recall their diagnosis, the stage of the disease, and the treatment that they received. This has many implications including that later in life they may either not inform new medical caregivers about their history or that their recall may be faulty.

> ***Example:*** *Rachel is a 54 year-old woman who was treated with adjuvant chemotherapy in 1995 for a node positive breast cancer. Her oncologist retired and in 2007, she developed a contralateral node positive breast cancer. No medical records were available and she did not recall which chemotherapy drugs she had received. With prompting she also did not recall if one of the chemotherapy drugs was, "red or yellow"!*

Cancer survivors need a clear and concise summary of all of the information listed above, but delivered in language that they can understand. This same report can also contain the important information that their medical team members need to provide good care.

The Cancer Survivorship Transition Off Treatment Care Plan

After a patient undergoes surgery, they typically receive discharge instructions that include a short description of the diagnosis and the procedure as well as what to eat, when and how to return to their regular activities, when to return for scheduled follow-up care, what symptoms should prompt a phone call or return to the hospital, and who to contact with specific contact information.

Similarly, cancer survivors benefit from a clear description of all the topics listed above including; their diagnosis, staging, surgery, radiation, and chemotherapy received. They need to know how often they should return to which of their care providers, what symptoms to look for, who to call, and how to reach them. Many cancer survivors also have other comorbid diseases and so reminding them to continue their regular medical care is important.

Finally, "cancer is a teachable moment" meaning that it is an opportunity for clinicians to educate patients about the importance of exercise, a healthy diet, smoking cessation, and ongoing cancer and other screening. Healthy cancer survivorship is the goal!

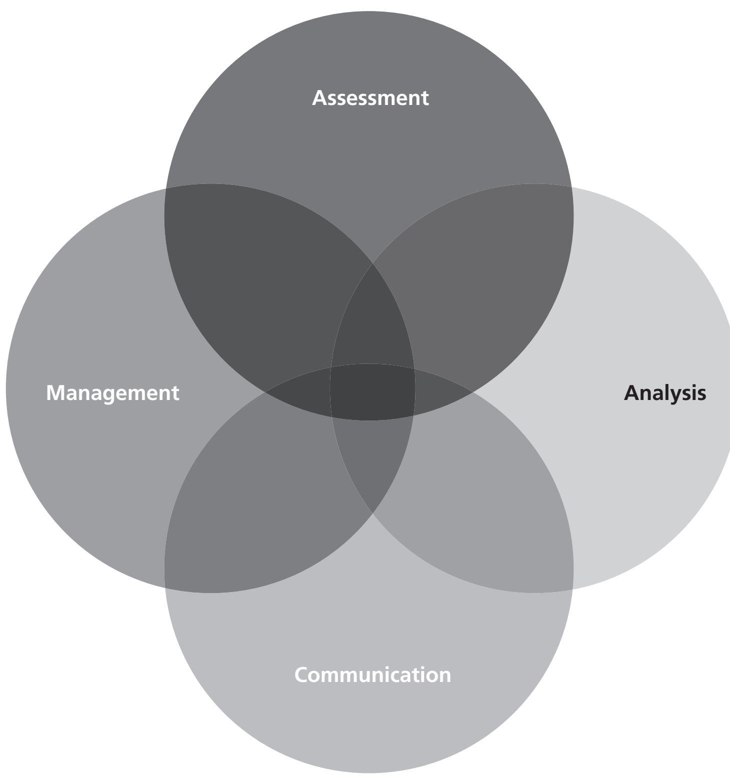
Late and Long-Term Risk Assessment and Long-Term Care Planning for Cancer Survivors

Cancer Survivorship Risk Analysis

Richard Boyajian, N.P., R.N., Dana Farber Cancer Institute

While there are many definitions of the word "risk," in the context of cancer survivorship, oncology providers should consider risk to be "The chance that a long-term/late effect resulting from a therapeutic exposure impacts a survivor's health." A therapeutic exposure is any chemotherapy, biological agent, radiation field or surgical intervention utilized to treat a survivor's malignancy. These therapeutic exposures, while necessary, may adversely affect the patients to whom they are administered.

Risk



Utilizing this definition, one can see why a complete treatment summary is the first step and perhaps the most important step in the process of survivorship risk analysis. Without the complete history of a survivor's therapeutic exposures, even the most knowledgeable provider will not be able to develop a proper risk assessment and ultimately will fail at any attempts of risk management.

Risk Analysis

A process consisting of three components: risk assessment, risk management and risk communication.

Risk Assessment

The World Health Organization defines risk assessment as "a scientifically based process consisting of the following steps: hazard identification, hazard characterization, exposure assessment, and risk characterization." This simple definition translates to the oncology/survivorship setting.

- **Hazard identification:** the identification of the therapeutic exposure capable of causing a long-term/late effect
- **Hazard characterization:** evaluation of the long-term/late effect associated with therapeutic exposure
- **Exposure assessment:** the determination of the relationship between the therapeutic exposure and the severity and/or frequency of the associated long-term/late effect.
- **Risk characterization:** the estimation of the probability of occurrence and severity of a known or potential long-term/late effect in a particular survivorship population.

Risk Management

A process of weighing guidelines options in collaboration with all of the cancer survivor's involved providers. This process considers risk assessment along with other appropriate factors for the health protection of the survivor. Appropriate considerations, such as, is the strategy cost effective, does it do what it is designed to do (efficacy), and is it reasonable to implement (practicality) must be taken into account. These and numerous other issues must also be considered when developing a risk management strategy that is appropriate for prevention, detection and control of long-term/late effects.

Risk Communication

The interactive exchange of information and opinions throughout the risk analysis process concerning hazards & risks, risks & related factors and risk perceptions amongst risk assessors, risk managers, consumers, industry, the academic community, and other interested parties. This includes the explanation of risk assessment findings and of risk management decisions. Again, this definition translates quite well to the oncology/survivorship setting. Risk communication is of utmost importance in survivorship risk analysis, primarily because the scientific evidence is weaker than we would like and most decisions are made by a consensus of all those involved. The interactive exchange of information and opinions is vital to the success of any such endeavor, and must involve all parties:

- **Risk assessors:** Oncology and Survivorship providers
- **Risk managers:** Oncology, Survivorship and Primary care providers
- **Consumers:** Cancer survivors
- **Industry:** The greater oncology community and insurance industry
- **Academic community**
- **Other parties**

Simply put, any one entity that tries to establish their own guidelines without involving others in the development process is ultimately setting themselves up for failure.

One Example of Late and Long-Term Survivorship Risk Analysis

Jill is a 35 year-old woman with a history of Hodgkin's Disease and Mantle Radiation

Risk Assessment

- **Hazard identification:** the identification of the therapeutic exposure (mantle radiation) capable of causing a long-term/late effect.
- **Hazard characterization:** evaluation of the long-term/late effect associated with therapeutic exposure. An estimate of the aggregate incidence of radiation-induced cardiac disease is between 10% and 30% by 5 to 10 years post-treatment. Up to 88% of patients have asymptomatic abnormalities of cardiac muscle, valves, pericardium, conduction system, and the vascular system.
- **Exposure assessment:** the determination of the relationship between the

therapeutic exposure and the severity and/or frequency of the associated long-term/late effect. Hull et al found a 10.4% incidence of CAD at a median follow-up of 11.2 years post-treatment. The results of at least one study suggest that the major modifier in the development of ischemic heart disease is the presence of traditional cardiovascular risk factors so that, at a minimum, a history of mediastinal radiation therapy could logically be added to that list.

- **Risk characterization:** the estimation of the probability of occurrence and severity of a known or potential long-term/late effect in a particular survivorship population. Radiation-induced cardiovascular disease is responsible for 1/4 of the deaths not directly attributable to HD with an increase in relative risk of 2.2 to 3.1. The risks associated with treatment total more than 40 Gy. The relative risk for myocardial infarction is 4.2 and 6.7 for myocardial infarction or sudden death.

Risk Management

In the setting of developing guidelines for the mantle irradiated patient, while we have epidemiologic data showing that this exposure does increase the risk of cardiovascular issues, we have limited to no data showing how we should screen or intervene in this subset of survivors. Based on the consensus of our radiation oncologists and consulting cardiologists, we have begun screening survivors with a resting echocardiogram and stress echocardiogram 10 years after their radiation exposure. We also have a clinical trial that has completed recruitment to evaluate these recommendations because there is not strong evidence to make this recommendation, rather there is a consensus based on the evidence that this is a risk. We expect to alter our recommendations based on the findings of our clinical study. In addition to the cardiac imaging, in consultation with our cardiology advisors and based on the literature we are now advising that any patient exposed to mediastinal/mantle radiation be considered at high risk (ATP III) in regards to lipid management by their primary care physician.

Risk Communication

The interactive exchange of information and opinions throughout the risk analysis process remains ongoing and as a clinical group we need to reach out to all involved parties if we ultimately want to achieve success in this area. Each of the survivors seen in the clinic sits down with a nurse practitioner, who explains the risk assessment findings and of risk management decisions. We are currently in the process of performing disease center based consensus committees to develop standardized risk analysis guidelines and propose to include all involved providers in this process. Ultimately, the success or failure of our standardized risk analysis will be based on communication, collaboration, and consensus.

What We Hear: A Conversation with Survivors

CT Challenge Survivorship Clinic Team
Pictured left to right: Scott Capozza, PT; Lina Chase, LCSW;
Maura Harrigan, RD; Thomas Quinn, R.N., CNS; Kenneth Miller, M.D.

After working with survivors of various types of cancer, some common themes and questions become apparent. In this section, a nutritionist, physical therapist, and a social worker address five of these common themes, as they would respond to the patient, from their specialist perspective, demonstrating how a multidisciplinary approach to survivorship enriches the care we provide. We should emphasize that each survivor is assessed individually. They bring a complex mix of factors to the encounter, so there may be significant variations in how the theme is presented and addressed in "real life."

Figure 5 **Five Common Patient-Centered Themes**

Concern or Question	Theme
"I'm worried about the cancer coming back. Is there anything I can do?"	**Fear of recurrence**
"I'm so tired!"	**Fatigue**
"I must have brought this on myself somehow."	**Guilt**
"I'm starting back to work soon. I'm looking forward to it, but I'm nervous, too. What if my boss expects too much of me at first? I've developed some healthy habits after my treatment and I'm afraid I won't have time or will get too busy to continue them."	**Concerns about returning to work**
"Other people have these expectations of how I should be and act and feel now that I'm 'over' the cancer. They really don't get it."	**Managing (unrealistic) expectations of others**

Physical therapist

Scott Capozza, P.T.

CT Challenge Cancer Survivorship Clinic

Fear of Recurrence: Exercising 5 times a week for 30 minutes a week may reduce one's risk of a recurrence or developing a secondary cancer by 40-70% depending on one's diagnosis. Exercise that increases your heart rate to 70-80% of your maximum heart rate (or a perceived exertion of 5-7 on a scale of 1-10, 1 being sitting on a couch and 10 being you are working so hard you feel like you are going to pass out) is the most effective intensity. Additional benefits of exercising after cancer treatment include weight reduction, improved cardiovascular endurance, increased muscular strength and improved mood. Exercising not only reduces one's risk of a recurrence of cancer but it also decreases one's risk for other chronic diseases such as diabetes and high blood pressure and reduces your risk of stroke and heart attack.

Fatigue: During and following surgery, radiation therapy and chemotherapy, your body may feel fatigued as it is healing from these treatments, and thus, you do not feel like exercising. A vicious circle can be created: you feel tired, so you don't exercise, and then you become more fatigued because you have not been able to increase your energy level by exercising, and so on. "The journey of 1,000 miles begins with a single step." Begin slowly and keep things in perspective. If you were exercising before you began your treatments, it will take you the same amount of time to regain your previous fitness level; if you did not exercise before your cancer diagnosis, you will see improvements at a faster rate. Aim for 30 minutes a day for 5 times a week as your long term goal. If this is too much to start with, begin with 15 minutes 3 times a week (a day on, a day off for rest) and increase each session gradually to 30 minutes; once you can do 30 minutes 3 times a week, then you can add a 4th day (beginning at 15 minutes, keeping your other 3 days at 30 minutes). Once you are able to tolerate 30 minutes of exercise on your 4th day, then add the 5th day in the same fashion. Setting specific goals (example: I want to be able to do a 3 mile walk for breast cancer by May without feeling fatigued) and writing your exercise routine for the week on a calendar are both good strategies to keep you motivated.

Concerns about returning to work: How can you return to work and still find ways to stay active or increase your activity level? If you work on the upper floors of an office building, take the stairs instead of the elevator (and if you work on the first floor, you can always walk up and down the stairwell several times anyway!) You can select a spot in the parking lot farther away from the building; if there is a shuttle to work from the parking lot, try to walk the distance once a day for two weeks, and then as you get stronger you can walk round-trip. If you plan on going to a gym or working out after work, bring your gym clothes with you to work, and change into them at the end of your work day. This way, you don't have to go home first to change and then potentially get distracted from your time to exercise. Encourage a co-worker (or two or three) to come with you on a lunch-time walk or an after work workout. Having a partner to exercise with makes the task more fun, it makes the time go by faster, it holds you more accountable, and you are getting somebody else to exercise and be healthy too! Talk to your co-workers and your supervisor about entering a corporate challenge at a local road race, bike event, or other activities such as a weekend hike. This will help get more people to be active and help build camaraderie amongst all of your co-workers.

Managing (unrealistic) expectations of others: If you exercised or were very active prior to your cancer treatments, it can take weeks and months to fully get back to your prior level of fitness, even if you "look like your old self." Strength and stamina return slowly. You may have had treatments that have long term effects that inhibit certain body functions (e.g., radiation treatments that scar the lungs, breast cancer surgery that limits range of motion in your shoulder), so you may not be able to fully get back to your prior level of activity.

Being able to explain your current limitations may be helpful. Telling people that you have a series of mini-goals or steps to get to a larger goal helps them see that you have thought the process through; it also holds you accountable to achieve these goals in order to make your ultimate long term goal.

If you need help getting back your strength or endurance, you can consult with a personal trainer at a gym. If you are experiencing a reduction or loss of range of motion, lymphedema, or other chronic condition as a result of your cancer treatments, you can seek the professional advice of a physical therapist, lymphedema certified therapist, or a licensed massage therapist. These professionals will be able to help you develop a plan to address barriers to your exercise plan. Have a plan in your head (putting in down on a calendar or your Blackberry is better) as to steps on your journey to regaining your physical fitness or in establishing your fitness plan for the first time. For example, you might set as a short term goal (2 months after finishing treatments) buying new shoes to exercise in and being able establish a good exercise routine. As a mid-range goal (4 months), you want to be able to walk for 30 minutes with 3-5 one minute running spurts in the middle of your walk. A long term goal (6 months) would be to run a local 5K road race without stopping.

Social Worker

Lina Chase, LCSW

CT Challenge Survivorship Clinic

Fear of Recurrence: Fear of recurrence is very common. It is important to realize that fear of the cancer returning is a projection into the future…we are **imagining** the future in a negative way. I suggest that, if we are going to use our imagination, then it is helpful to use it in a positive way and imagine yourself as healthy. (There are visualizations and affirmations that can be helpful in projecting into the future). Best of all, there are techniques to assist in keeping us in the present. Meditation or mindfulness and conscious breathing bring us into the present moment. There are numerous books, CDs and DVDs that are presently available, as well as classes in most communities to learn these skills. We have a survivor support group following individual sessions in our clinic that includes a short conscious breathing/mediation practice.

Fatigue: First of all, please know your concern is felt by most cancer survivors. Frankly, as a non-medical professional, my answer will be one of an observer. It appears that most medical professionals want to reassure cancer survivors and tend to underestimate the amount of time it takes to return to a previous level of energy. I believe this is so because the doctors (and other medical professionals) hope that their patients will have an optimistic attitude, and the optimism will assist in recovery. My suggestion is to trust your body and attune to what you can do. In yoga, it is called "the edge," meaning go to the edge of what you can do, without pushing so hard that you go over (the edge). The key is self acceptance and patience; it is important to trust your body and allow the necessary healing to take place before returning to "normal" functioning.

Guilt: We seem to have a "little voice" that whispers in our ear, "you did something to cause the cancer." There is no evidence to back this up. Cancer survivors are a diverse group: all ages, all races and religions and socio-economic groups. We are omnivores and vegetarians, alcohol consumers and teetotalers, couch potatoes and fitness buffs and everyone in between. (It is also true that some nonsmokers get cancer and some smokers do not.) That said, good habits serve us well…eating healthful foods, regular exercise, adequate sleep and relaxation, laughter, light alcohol consumption, loving relationships, and having fun…will improve quality of life and assist us in staying healthy.

Concerns About Returning to Work: Communication and flexibility are the keys to transitioning back to work. Have a head-to-head/heart-to-heart conversation with your boss and communicate your reality. The contemporary work place seems to have more options for survivors. Do you need to temporarily (or permanently) reduce your hours/days at work? Is it possible to work some hours/days from home via computer? Honesty is usually the best policy and most employers want to support their employees for a myriad of reasons.

Managing (unrealistic) expectations of others: Communication is key, both verbal and behavioral. It is important to speak to family members, expressing your reality. Perhaps you are looking like you did before cancer externally; yet, this is not your internal reality. It is also important to express your reality in action, as well as words. If you are not up to a task, **don't do it!** Remember, too, that your loved ones are also experiencing a loss—the old you, and the comfort of a healthy you in familiar family roles. Working out this new reality requires open communication. It might be useful to have professional help facilitate the adjustments or to help the family develop new communication skills.

Maura Harrigan, R.D.

CT Challenge Survivorship Clinic

Fear of Recurrence: There is no one food that will trigger a recurrence. In fact, eating a healthy diet may help prevent recurrence. In addition, a nutritious diet will manage your weight, improve cardiovascular health, and help manage your blood pressure, cholesterol levels, blood glucose levels and even your mood.

The ideal diet plan is outlined below:

- **Eat a predominately plant-based diet** rich in vegetables, fruits and whole grains.

- **Eat a rainbow of colors of fruits and vegetables**
  Each color represents a different constellation of vitamins, minerals and phytonutrients packaged by nature to act in synergy. Eating at least 5 servings of fruits and vegetables a day as whole foods has a potency not found in use of supplements.
- **Limit consumption of processed and red meats.** Think of meat as a condiment.
- **Emphasize omega-3 fatty acids**
  Omega-3 sources (salmon, eggs fortified with omega-3, flaxseed, fish oil supplement) may have specific benefits for cancer survivors.
- **Observe food safety practices**
  It is important to protect your immune system from food-borne illness.
  - Wash hands often. Keep hot food hot (>140°F), keep cold food cold (<40°F). Do not thaw frozen food on the counter. Thaw in refrigerator or microwave.
  - All raw meat, fish or poultry is handled with separate cutting boards, dishes and utensils. Never let cooked food touch anything used to handle raw food.
  - Change sponges and dishtowels often.
  - Thoroughly wash raw fruits and vegetables.
- **Limit consumption of alcohol**
  Moderate drinking is one drink per day for women and 2 per day for men.

Fatigue: "I am too tired to food shop, cook, even at times to eat." As explained above with exercise, the same vicious circle can be created: you feel tired so you skip meals then you become more fatigued because you are not giving your body enough fuel and nutrients. Eating 5-6 smaller meals throughout the day helps sustain your blood glucose levels which makes your feel more energized. It is important to have a source of protein at every feeding (cheese, skim milk, nuts, peanut butter, eggs, fish, or lean meat). Also have 2 types of high fiber foods at every feeding (whole grain breads, crackers, cereals, any fruit, or any vegetable).

This combination of protein and fiber helps raise and sustain your blood glucose levels giving your body a steady source of fuel. Even if your appetite is low, it is better to have a few bites of each of the protein and high fiber foods than trying to eat all of only one food item.

Be careful to avoid falling into the trap of eating sweets for quick energy. This in fact creates more fatigue and sets you up to crave more sugar and another vicious circle of fatigue continues.

Be willing to ask for and accept help from family, neighbors and friends with food shopping and meal preparation. Take advantage of home delivery service offered by supermarkets. Having healthy food stocked and readily available in your home and work environment will make eating well throughout the day easier.

Guilt: Just as there is no one food that will trigger a recurrence, there is no one food which caused your cancer. As explained by the physical therapist above, there are many variables or risk factors for developing cancer. Even individuals whose customary diet has been very nutritious are still at risk for developing cancer. But continuing, or putting into place, nutritious eating habits will improve energy levels and boost the immune system. Let's not forget eating food is fun and delicious.

Concern about returning to work: Returning to work can present many obstacles to eating well. None of which can't be met with a thoughtful plan and a good food shop to arm yourself with on-the-go foods. The first challenge is making sure you schedule the time to eat within your hectic day. This starts with a mandatory breakfast. Either at home or at your desk, eating something quick like a bowl of high fiber cereal with berries and skim milk energizes your day. The work environment itself can present many hazards: candy bowls on desks, danish by the coffee maker, the vending machine down the hall. Stock your work area with healthy snacks such as dried fruits, yogurt, or nuts. Try to enlist your co-workers to establish a healthy-food-only office policy to benefit all. Lunch provides a much needed mental and physical recharging. Brown bag lunch (a simple sandwich or dinner leftovers, a piece of fruit) then take a brisk walk with co-workers. The late afternoon snack is essential to eat either at work or on the commute home. This is a natural low energy time. Don't fight it, fuel it. A piece of fruit and some cheese or nuts will take the edge off your hunger. You don't want to arrive home ravenous thereby setting yourself up to overeat at dinner, or worse, continually grazing throughout the evening. When you fuel your body throughout your workday, you'll find that dinner becomes your smallest meal. For those who work evening and night shifts, adapt your eating schedule to fit your work hours even if that means your "breakfast" is at 11 PM and "dinner" is at 7 AM.

Managing (unrealistic) expectations of others: To continue in the spirit of the words of the social worker, you may not be able to, nor may you want to carry on your familiar family role regarding food shopping, meal planning and cooking. The recommended predominately plant-based way of eating does not require you to prepare a special meal for yourself then a different meal for the rest of your household. All members of your household will benefit from this way of eating. Again, communicate your needs. Enlisting the help of members in your household will help you all adopt new ways of healthy eating over time.

Lessons Learned: The CT Challenge Survivorship Clinic

Pictured left to right: Scott Capozza, PT; Lina Chase, LCSW; Maura Harrigan, RD; Thomas Quinn, R.N., CNS; Kenneth Miller, M.D.

These are ideas based on the experience of one clinic. They may or may not apply to your setting, population, resources, or needs.

Things to consider as you contemplate implementing a survivorship program.

Your vision

Starting a cancer survivorship program is an exciting undertaking. We recommend that before you start seeing cancer survivors that you work hard at developing your conceptual underpinning. There are a lot of issues and questions to address as you plan the structure of your program. These are the same kinds of questions that need to be answered for any new program;

- What needs are you addressing?
- Which of these needs are patient-oriented and which are institution-oriented?
- What is your philosophy? What are your goals?
- What is the desired outcome—what will the patient take away?
- Can you describe what your program will look like when you open your doors?
- What do you want it to look like after a year, and three years?

The Connecticut Challenge Clinic Vision

At its core, the Connecticut Challenge Cancer Survivorship Clinic is a health promotion program for people with a recent diagnosis of cancer. Our target population is adults who have recently completed acute treatment for cancer. As such, we are sensitive to rehabilitation needs, the requirement for periodic surveillance, and transition points as opportunities for growth and adoption of new, healthy habits and relationships.

Institutional culture and support

You may find that the institutional culture and structure are welcoming for the creation of a new program or alternatively that these can't or won't support your vision. You may therefore have to adjust your sights. Even if you have philosophical buy-in, are the resources available (time, people, space, etc.) that you will need to implement your vision?

It is difficult to generalize about the challenges that cancer survivorship programs will face in academic or community hospital and practice settings. Some of the common spoken and unspoken issues facing a new survivorship program include previous or ongoing issues between cancer caregivers and then the new challenge of which members of the cancer care team feel included in creating this new program and who feels threatened by it or not included.

A very specific issue that arises in cancer survivorship is the role of the primary oncologist who often has known the cancer survivor for many years. Many feel that they know the patient well and don't feel that it is necessary for other care providers to become involved. Other oncologists feel that they have a key role to play in the survivor's ongoing care but see survivorship programs as a "value-added" program to stress wellness. Finally, in some settings Oncologists may feel that the cancer survivor can receive their care exclusively in a long-term cancer survivors follow-up clinic and/or with their primary care provider. Each of these approaches needs to be respected and accommodated.

The Connecticut Challenge Survivorship Clinic / Yale Institutional Culture and Support

The CT Challenge Survivorship Clinic is located at the Yale Cancer Center. Our cancer center Director, Dr. Richard Edelson and the Chairman of Medical Oncology, Dr. Edward Chu, have a strong commitment to adding a cancer survivorship program to the host of care services that are available to patients and their families. There were logistic challenges to overcome in regards to allocating funds for part-time survivorship staff in nutrition, exercise/PT, and social work while taking into account the existing staffing in each of these cancer center departments and the mission of these departments regarding care for patients who are "on treatment" vs. "post-treatment."

Referral of patients to our program and to others nationwide is also an interesting topic. Briefly and succinctly, some oncologists refer many patients to the survivorship programs while many others do not. The referring oncologists generally have felt that their patients are receiving special services that are often not available for patients who have finished treatment. The doctors who have not referred may not actively think about the survivorship clinic during their busy day or may honestly feel that they and their own team are already providing this care.

Structure

Nationally, specialized cancer survivorship care is provided in many different ways and by different care providers. In many settings, the care is directed at a specific group such as breast cancer survivors while other programs provide care for a broad group. Aside from this, there are several common models of care including:

- A one-time survivorship consultation at the end of treatment with a single care provider such as a nurse practitioner focused on healthy survivorship.
- A one-time survivorship consultation at the end of treatment with a multidisciplinary team focused on healthy survivorship.
- A short series of visits soon after completion of treatment with either one provider or a team.
- Care for cancer survivors at any time after their initial therapy that is problem-focused (for example: post-mastectomy pain, lymphedema, other pain problems, cognitive dysfunction, fatigue, sexual health problems, anxiety, depression).
- Assumption of a cancer survivor's ongoing follow-up care typically several years after their initial therapy was completed and at a time when the risk of recurrence is low.
- Many combinations of the above.

The Connecticut Challenge Survivorship Clinic's Structure

In order to implement our philosophical perspective, which is inherently holistic, we need a multidisciplinary team. In our case, we find that a nutritionist, physical therapist, social worker, and advanced practice nurse or Oncologist are able to bring the perspectives, skills, and knowledge that provide a well-rounded experience for our patients. We wouldn't be able to deliver clinical services with anything resembling coherency if we did not also have a program coordinator, who is an integral part of the team. It is certainly not essential, but we find that having cancer survivors on our team provides a nuanced perspective. The diversity of their personal experiences with cancer helps to keep us mindful of the heterogeneity of our population.

The specifics:

How we do it?

During a clinic session, each patient spends at least 30 minutes with each clinician. Then there is a group session facilitated by the social worker. In the group, the patients share a little about their own cancer experiences and learn take-away skills such as breathing for concentration and relaxation. Most patients are also given written "prescriptions" for incorporating healthy nutrition and exercise practices into their lives. They are encouraged to resume or maintain relationships with primary care providers who will have a central role in future health screenings and maintenance. They are also given information on potential long term or delayed sequelae to cancer and its treatment. As appropriate, referrals for genetic counseling and community resources are made. Patients are invited to return at 2-month intervals for a total of three visits. Our follow-up visits permit us to validate and support, coach, and tweak care plans. Sometimes, in the interim, new challenges have arisen for the patient that we can address directly or through referral to appropriate institutional or community resources.

How the survivors get referred or self-refer

Most patients have received their cancer treatment at Yale Cancer Center, although we are happy to see patients from outside our system. They are referred to us by a physician or nurse at or shortly after completing their acute treatment; some patients remain on maintenance or preventative therapies. A portion of our patients are "word of mouth" referrals from other patients from YCC or the community. We have done very little marketing, although the YCC public relations office has helped up with brochures and a website. We have also had referrals inspired by our education programs.

Teaming

We're a small program and everyone on the team works part-time. We therefore have to work hard at maintaining communication and keeping the bureaucratic elements working smoothly and in synchrony with other parts of the Cancer Center structure (scheduling, billing, clinic operations, etc.) We find periodic team meetings to be very beneficial for sharing perspectives, strategizing about particular patients, identifying trends, planning for the future, and providing peer support. Increasing the frequency of team meetings (approximately 2 per month) has solidified our sense of "teamness" and enhanced the evolution of our model.

Keeping it running

Our coordinator, as the name implies, makes it all work so that the clinicians can do their clinical work. She is the initial "voice" of the clinic, as people call in. She explains how the clinic works, sends out intake forms, and makes appointments. On clinic day, she creates a schedule for each patient and clinician, prints out pertinent records, and prepares a folder of information for the patient. She also monitors our time so that the patient can get the benefit of a full session with each clinician.

Continuing development

We evolve through observing our practice, paying attention to what we hear from patients, and "talking it out" in team meetings. Patients also fill out an evaluation form at the end of the group session, so we have semi-anonymous feedback from them. One of our frustrations is lack of time outside of clinic hours for more formal or concentrated program development.

We can serve only a very limited number of patients using our current model. We need to develop creative and structured processes for addressing at least the basic informational needs of patients who do not come through the clinic.

Among the things we have observed or heard from our patients is that they are a bit uncomfortable coming into a cancer clinic setting for our Survivorship Clinic (should we even call it a 'clinic?'). If we were designing from the ground up, the space we use for seeing patients would be 'homey,' not clinical. We don't know how many patients choose not to come at all because it means coming back to the place where they received their diagnosis and (often unpleasant) treatments.

We would also expand what we are able to offer patients beyond our one-to-one consultations. For example, a small kitchen would permit the nutritionist to teach and demonstrate good nutritional practices. It would be welcoming and soothing, enhancing the patient's ability to learn and explore new behaviors. Dedicated space with exercise equipment would permit more thorough functional assessments by the physical therapist, as well as extend teaching and evaluation capacities. Comfortable space for support groups, employing cognitive-behavioral interventions/skills, and use of low-technology interventions such as Reiki would enhance the psycho-social offerings of the social worker. Space for seminars and presentations would provide additional opportunities supporting the informational needs of patients and their families.

More on the CT Challenge Survivorship Clinic: Lessons learned, the hard way!

Lesson One: Initial screening and information provided to the patient prior to coming to the clinic are important because:

- Some patients may not really understand why they are coming or the nature of the visit.
- Some patients are too close to diagnosis and treatment to benefit from our model.
- Some may not understand the services that are available and not available. One patient calling from outside our system was referred to the clinic by the central appointments office. She was a cancer survivor, but she was looking for a referral for migraines, not cancer-related issues. Another brought her work-out clothes to clinic.

Lesson Two: It's harder to work with the patient—and inefficient—if we don't have information on the patient in advance. Patients who don't complete the intake form or don't bring outside records don't receive optimal care.

Lesson Three: Internal marketing and networking to get institutional buy-in need to begin well before the clinic sees its first patient. Initiatives also need to continue, and established relationships between patients and other clinicians need to be fostered and reinforced.

Lesson Four: Automating some aspects of survivorship care would be helpful. One problem we have is the lack of an established process within our records system for creating a treatment summary that we can review prior to seeing a patient and that we can give to the patient to share with other providers. We are working on developing a data base that will help to automate the process. In the current structure, it is time-prohibitive to pull disparate elements into a succinct document. Similarly, the treatment plan the patient receives is less formal and complete than it should be.

Lesson Five: Having spouses or other family members accompany the patient is often beneficial. However, we sometimes need to work to keep the focus on the patient as the primary clinical dyad.

Lesson Six: Measuring outcomes is important. Aside from the evaluation forms and comments of patients, we don't know whether we are making a real impact or not. Our sense is that we are, but we have no data that permits us to say with confidence "we're really making a positive difference" for our patients. We have a limited study under way regarding timing of clinic attendance, but we do not have the resources to conduct further research. We are aware that there are other models for delivering services to cancer survivors. We are looking forward to seeing the development of a research base on survivorship interventions.

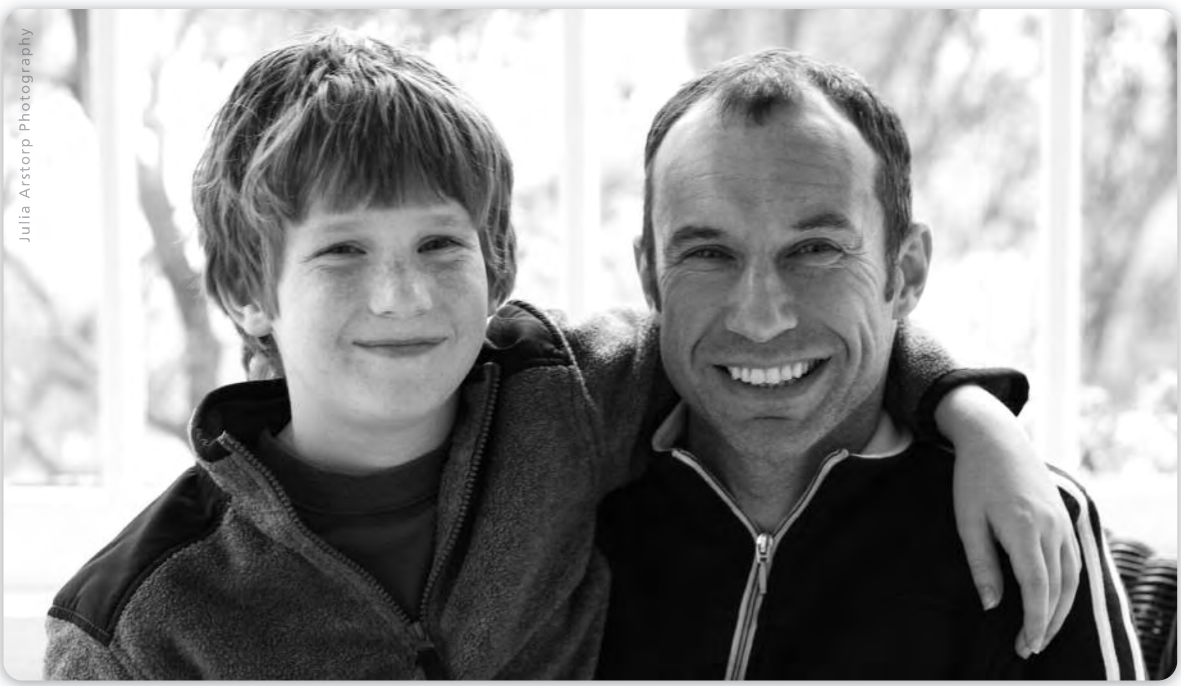
Cancer Care in the Community

Maureen Flynn, MPH, Dana Farber Cancer Institute

During the past 1 ½ years, we have learned a great deal about what works and what doesn't work for cancer survivorship care in community settings. What cannot be disputed is the need for community based survivorship care. Many of the patients we have seen in our community settings are examples of what the IOM report dubbed "cancer survivors - lost in transition." Neither these survivors nor their primary care providers report being adequately aware of the risks from the treatment received or of the recommendations to mitigate or lessen these late effects. Without exception, every patient we saw in our community settings needed some medical and psychosocial support as well as knowledge about community based resources.

Our work with the South Boston Community Health Center (SBCHC) taught us that our "boutique" clinic model was not the most efficient or effective way to deliver survivorship care in a community setting. Our model is expensive and does not lend itself to unscheduled walk-in patients or no-show patients. Much to our surprise we learned that learning more about the risks of late effects was not a sufficient motivator for cancer survivors to schedule and keep appointments at our South Boston Survivorship Clinics. Building on what we have learned from our pilot project, the SBCHC Medical Director will pilot a different model during the next few months. This new model will look at ways that integrate survivorship care into the primary care visit. This model will include in service education sessions for all (SBCHC) primary care providers, all cancer survivor will receive general wellness information about cancer survivorship care (toolkit) at a visit with their SBCHC primary care provider and every cancer survivor (patient with a history of cancer) will be sent a letter from the PCP recommending that the cancer survivor patient schedule an appointment with cancer survivor specialist(s) and receive a treatment summary and care plan using Oncolife.

Whittier Street Health Center opened it Cancer Survivorship Clinic in the late fall of 2008. The Executive Director, who is deeply committed to the success of this clinic, anticipated the problem of "no shows" and instituted a case management model that has been very successful. Coupled with offering the clinic during the evening hours as well as day time hours, Whittier Street's clinic has been over-booked since opening its doors. Whittier Street's medical director tailored our staffing model to fit the primary care setting. Instead of using a NP, a LICSW and a scheduler (DFCI's



"When someone first referred to Luke as a cancer survivor rather than as a cancer patient, I was shocked. Survivorship seemed an afterthought: we were so focused on the next treatment, the next procedure, the next test, that we had skimmed over all of the issues that, thank goodness, are now so important."

– Martin Whittaker / Darien, CT

model), Whittier Street is using an RN, a LICSW and two case managers. This staffing model is working well and is proving to be both efficient and effective. Additionally, Whittier Street Cancer Survivorship Clinic is offering a wide variety of services including medical and psychosocial evaluation and referrals, coordination through patient navigation and case management and monthly education classes focusing on wellness and self care. Future plans include testing an innovative model of navigation that locates the navigator in the patient's primary care setting rather than in the oncology setting. It is hoped that this model will identify and eliminate barriers from initial diagnosis to the end of treatment and ensure a smooth transfer back to primary care and keeping primary care "in the loop" throughout the whole process. The navigator will also act as an educator to primary care providers regarding oncology and oncology care. Our plan is to test this model with a large primary care practice (community health center) serving disadvantaged women and men. If successful, the next step would be to figure out a way to deliver this same quality of care to patients in smaller practices in less populated regions of the region.

As we enter the final year of funding from the LAF, we will focus on developing our clinic model approach to provide community based survivorship care and focus on helping our affiliates use their primary care capacity to deliver state of the art survivorship care.

At our oncology affiliate, New Hampshire Oncology/Hematology (NHOH), our focus is on testing the efficacy and sustainability of providing every patient and their primary care provider with a treatment summary and care plan during a transition visit at the end of treatment. The goal is to identify and measure the key components of the transition from oncology care to primary care including implementing programs that educate both patients and primary care providers about the special needs of cancer survivors. NHOH staffing includes two physicians and a social worker. The team is supported by an administrative assistant. Future plans include testing the efficiency and effectiveness of a centralized capacity to create treatment summaries and care plans thus removing this time consuming burden from the provider. DFCI will work closely with NHOH in the development of integrated treatment summaries and risk assessment plans for patients transitioning from active therapy. The focus will be on the usability of the product, and how it fits into the workflow of physicians, nurses, physician assistants, and support staff. The project that is being implemented will allow DFCI to gain considerable insight and experience in how to use these tools in a practice such as NHOH's.

Building from a statewide survivorship summit held in May of 2008, the CBC is working to change the current medical paradigm of Massachusetts by creating a state-wide system change. Working with the Massachusetts Comprehensive Cancer Control Coalition and the Department of Public Health (DPH), the CBC is collaborating to amend licensing requirements for all oncology practices and centers in Massachusetts to include treatment summaries and care plans as a requirement for licensing by the Department of Public Health. This project will begin with a statewide assessment of all oncology practices conducted by the Department of Public Health. Concurrently, a team headed by DFCI will develop educational programs and materials for oncology and primary care practices in MA to facilitate this transition and a work group, headed by DPH will invite MA payors to assist in the development of the technology necessary to complete this transition to a new standard of care for cancer survivors. Three states will also be invited to join in this pilot program.

Since the winter of 2008, the CBC has conducted patient education sessions called Listening and Learning Sessions for more than 600 cancer survivors (with a focus on medically underserved survivors), published 10 articles and produced two cable news programs on survivorship issues in collaboration with our community partners. During the next 6 months, our plans include creating a patient and provider library of web based products, printed materials and DVDs that further the understanding and expertise of cancer survivorship care.

Over the next year, our goal is to reach cancer survivors where they work and live. To do this, we will partner with community groups cancer and non cancer focused organizations, and the media. We will enhance our outreach capacity by building on our very successful model with Boston's Pink & Black Coalition –*"Ambassadors for Survivorship"* program with a focus on closing the gap for underserved communities in the region. We plan to use the Blum Van and our community partnerships to enhance cancer care planning capacity by instituting our "survivorship on the road" program and continue to provide Listening and Learning sessions for cancer survivors expanding our program to other regions in New England. We will develop survivorship education and support programs at our DFCI satellites.

Our work with MassConect (an NCI grant of the Harvard School of Public Health) continues to focus on creating a model community health center that would provide excellence in care encompassing prevention, detection, screening, access to treatment, and survivorship care. Upon completion this model will be made available to community health centers across the nation.

"Adherence to the dietary recommendations along with maintaining a healthy weight and adopting a physically active lifestyle, remains the best strategy for survivors."

Susan T. Mayne, PhD

Nutrition and Prevention for Cancer Survivors

(Adapted from *Medical and Psychosocial Care of the Cancer Survivor,* Jones and Bartlett, *In Press*)

Susan T. Mayne, PhD and Stephanie Materese, MPH, MA

Dietary recommendations for cancer prevention and survivorship focus on the following areas: (1) maintaining a healthy weight; (2) limiting intake of high-fat foods, particularly from animal sources (not an official ACS guideline but a topic of recent research and lay interest); (3) emphasizing consumption of plant food sources, specifically 5 or more servings of vegetables and fruits every day; (4) choosing whole grain products instead of refined grains; (5) limiting consumption of processed and red meats; and (6) limiting alcohol consumption (for those who choose to drink alcoholic beverages).

Maintain a Healthy Weight

Recent evidence indicates that obesity increases the risk of many more cancers than has been previously recognized. As an example, in the American Cancer Society Cancer Prevention Study II, a longitudinal cohort study, obesity was shown to increase the risk of dying due to numerous cancers. This study confirmed the known relationship of obesity to risk of dying of various cancers, like colon and prostate, as has been found in previous studies, but the analysis revealed some surprising findings as well. Of particular interest, there was a 52% and 88% increase in the risk of all cancer death for men and women respectively who are severely obese as compared to men and women who are normal body weight.

Limit Intake of High-Fat Foods, Particularly from Animal Sources

The Women's Intervention Nutrition Study (WINS) was the first randomized clinical trial of a dietary intervention in breast cancer survivors. Initial results of the trial, published in 2006, showed that the relative risk of second breast cancer in the women who were randomized to the low-fat diet was 0.76 (95% CI, 0.60-1.00; P=.03), translating to a 24% statistically significant reduction in risk. Of particular interest, when the results were stratified by the estrogen receptor (ER) status (positive vs negative) of the women's first breast cancer, a more substantial benefit was observed in women who had ER-negative breast cancer (RR: 0.58; 95% CI, 0.37-0.91).

Consume 5 or More Servings of Vegetables and Fruits Each Day

The American Cancer Society and many other organizations continue to recommend consumption of at least 5 daily servings of a variety of fruits and vegetables. One panel concluded that higher intake of plant foods (including nonstarchy vegetables and fruits) reduced the risk of various cancers, with strongest effects noted for oral, pharynx, larynx, esophageal, and stomach cancers.

Choose Whole Grains Over Refined Grains

Whole grains contain many micronutrients (eg, vitamin E) and macronutrients (eg, dietary fiber) in comparison to refined grains. From observational research, we know that people who have a higher intake of whole grains and fiber have a lower risk for many different cancers, especially colorectal cancer.

Limit Consumption of Processed and Red Meats

A large body of evidence indicates that intake of red and processed meat increases the risk of colon cancers. The recent World Cancer Research Fund/American Institute for Cancer Research report evaluated the link between meat intake and colorectal cancer risk, and determined it was "convincing."

Limit Alcohol Consumption, If You Drink at All

A large body of evidence clearly demonstrates a synergistic interaction between alcohol consumption and tobacco use in raising the risk of many epithelial cancers, including oral cavity, pharynx, larynx, and esophageal squamous cell carcinoma. Moderate alcohol consumption is also associated with an increased risk of breast cancer.

Supplemental Nutrients

Among cancer survivors, there has been much interest in nutrient supplementation for cancer prevention. Results are now available both from trials looking at primary prevention of cancer incidence within healthy populations as well as secondary prevention of cancer recurrence in cancer survivors. The clinical trial evidence supporting cancer preventive effects for nutrient supplements is inconsistent, with some trials showing benefit, some showing mixed results, and others showing harm.

Conclusion

Cancer survivorship research remains a relatively young field, and the evidence base demonstrating that nutritional interventions can improve outcomes in cancer survivors remains limited. Thus, heavy reliance is placed on a larger body of literature that describes dietary patterns that may reduce the risk of cancer in general and have been proven to reduce the risk of many other chronic diseases. Adherence to the dietary recommendations, specifically emphasizing plant food sources and whole grains while limiting consumption of processed and red meats, should be a goal for all survivors. This goal, along with maintaining a healthy weight and adopting a physically active lifestyle, remains the best strategy for survivors.

■ Physical Activity after a Cancer Diagnosis

(Adapted from *Medical and Psychosocial Care of the Cancer Survivor,* Jones and Bartlett, *In Press*)

Melinda L. Irwin, PhD, MPH
Associate Professor, Yale School of Public Health

Melinda L. Irwin, PhD, MPH

Physical Activity and Cancer Survival

A growing number of studies have recently been published demonstrating that participation in physical activity after a cancer diagnosis is associated with improved colorectal and breast cancer survival. These studies have demonstrated an approximate 50% reduction in the risk of recurrence, total deaths and cancer-related deaths. While any amount of recreational physical activity performed after diagnosis was associated with improved prognosis, the maximal benefit occurred with participation in 3 hr/wk (or 30 min of continuous exercise on most days of the week) of moderate-intensity exercise, such as brisk walking. These studies also showed improved prognosis in overweight and normal weight men and women, and those with higher stages of disease.

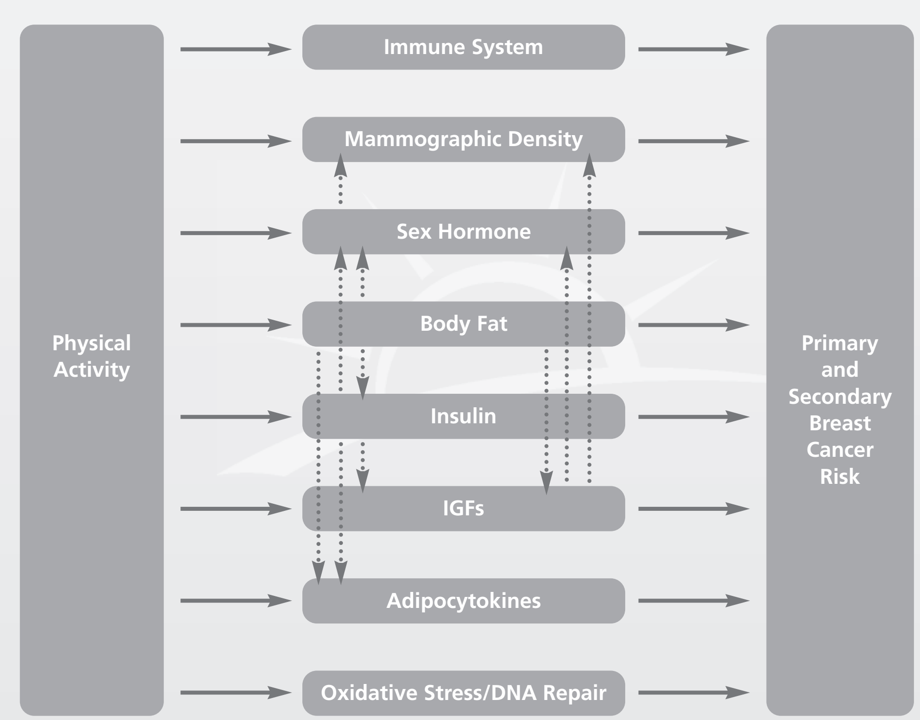
Physical Activity and Cancer Survivorship

Many studies have also observed associations between higher levels of physical activity and improved quality of life, decreased anxiety, depression, and fatigue during and after cancer treatment. Favorable effects have been observed for both aerobic and resistance exercise on self esteem, fitness, and body composition, as well as increased chemotherapy completion rates compared with usual care. Furthermore, no significant adverse events have been reported (e.g., lymphedema has not been shown to increase or be exacerbated by aerobic or resistance exercise). Overall, these studies have demonstrated that exercise is safe in cancer survivors and produces beneficial effects on quality of life, cancer-related symptoms with no adverse side effects, and improved prognosis.

Mechanisms Linking Physical Activity to Improved Cancer Survival

The beneficial effects of physical activity on cancer survival may be mediated through a reduction in body fat, and beneficial changes in metabolic (e.g., insulin) and sex hormones (e.g., androgens and estrogens), growth factors (e.g., insulin-like growth factor (IGF)-I and IGFBP-3), adipokines (e.g., leptin, adiponectin), and/or inflammation (e.g., C-reactive protein). In a recent publication, moderate-intensity aerobic exercise, such as brisk walking, performed for approximately 120 min/wk, was associated with modest, yet favorable, changes in body fat in postmenopausal breast cancer survivor. A dose-response effect was also observed with greater decreases in body fat occurring with higher doses of exercise per week. Exercise also decreased insulin and insulin-like growth factors by clinically meaningful amounts.

Figure 6 Hypothesized relationship between physical activity and primary and secondary breast cancer risk



Strategies for Increasing Physical Activity after a Cancer Diagnosis

Becoming physically active is a difficult challenge for healthy adults and is likely to be even more difficult after a cancer diagnosis and during medical treatments. In reviewing papers that examined predictors of physical activity adoption and maintenance in healthy men and women and cancer survivors, a physician's recommendations to exercise has been shown to be a strong predictor. Survey studies have also shown that cancer survivors want to receive information about physical activity. Oncologists should become aware of the benefits of exercise, assist their patients by endorsing existing physical activity guidelines and refer their patients to certified cancer exercise trainers.

Most recently, working together, the American Cancer Society and the American College of Sports Medicine developed a certification called "the certified cancer exercise trainer" for personal trainers, physical therapists, nurse practitioners or other health professionals to become certified in counseling and training cancer survivors in how to exercise safely and at recommended levels. These "Certified Cancer Exercise Trainers" are knowledgeable of the potential physical limitations associated with surgery and treatment, and have the skills and abilities to help cancer survivors overcome some of the recent and late effects of surgery and treatment (go to www.acsm.org for more information).

In regards to when to initiate an exercise program after diagnosis, some scientists and oncologists feel the timing of physical activity programs may be critically important because the teachable moment may best be capitalized on if programs are offered soon after diagnosis. Certainly issues such as concurrent demands of treatment are key concerns in the timing of programs, and therefore appropriate balance is necessary in determining the optimal time at which the patient is both physically and psychologically ready to undertake behavior change.

Summary

One of the most common questions cancer survivors ask is: "What can I do to improve my survival?" Physical activity is a modifiable behavior with a multitude of health benefits. A growing number of publications show a strong relationship between physical activity and cancer survival. Numerous observational studies have also demonstrated that obesity and weight gain adversely affect cancer prognosis, adding further evidence to the hypothesis that physical activity, one of the critical components of obesity and weight gain, influences cancer survival.

Furthermore, many existing cancer therapies are costly and have significant side effects that can result in long-term morbidity. Therefore, non-pharmacologic methods, such as participating in physical activity to lower the risk of cancer mortality, especially methods that are also associated with improvements in quality of life and other chronic diseases, may offer an attractive addition to the currently available treatment options. Oncologists and primary care physicians should be encouraged to counsel their patients proactively about physical activity. The simplest, evidence-based recommendation at present would be to undertake 30 minutes of moderate-intensity recreational physical activity, such as brisk walking, five times per week. Since a majority of cancer survivors are not currently participating in recommended levels of physical activity, resulting in greater disease risk and health care costs, this therapy has the potential to benefit a large number of cancer survivors.

The Need for Ongoing Cancer Screening and Surveillance

The Epidemiology of Second Primary Cancers

(Adapted from *Medical and Psychosocial Care of the Cancer Survivor,* Jones and Bartlett, *In Press*)

Andrea Ng, MD, MPH and Lois B. Travis, MD, ScD, University of Rochester, Strong Memorial Hospital Cancer Center

The diagnosis of a new cancer represents one of the most devastating events experienced by cancer survivors. The number of survivors with second or higher order cancers is increasing rapidly; these independent malignancies comprised about 1 of every 6 (16%) cancer incidents reported to the National Cancer Institute's (NCI's) Surveillance, Epidemiology, and End Results (SEER) program in 2004. Moreover, solid tumors are a leading cause of death among several groups of long-term survivors, in particular, patients with Hodgkin disease (HD). Second cancers can reflect the late effects of therapy, the impact of lifestyle choices (eg, alcohol or tobacco use), host factors, environmental determinants, and the operation of joint effects, including gene-environment and gene-gene interactions.

It is critical to continue to describe and quantify the risks of second malignancies. Moreover, the evolving patterns have important implications for patient counseling and the recommendation of behavioral changes, cancer screening, and prevention strategies. Where efficacious screening methods (eg, mammography) are available, these modalities should be included in patient follow-up, as indicated, including women treated for HD at a young age with the wide-field, high-dose chest radiotherapy treatments of the past. Preventive approaches (eg, smoking cessation, avoidance of ultraviolet light) may also decrease the risk of selected second cancers, and cancer survivors should be strongly advised to implement practices consistent with a healthy lifestyle. An improved recognition and understanding of therapy-related second malignancies can inform modifications in regimens to minimize exposure to cytoxic agents.

Example: Hodgkin Disease

The increased risk of therapy-related leukemias in HD patients is highest in the first 10 years after treatment. The elevated risk is largely due to alkylating agent chemotherapy, with the existence of a strong dose-response relationship. Radiotherapy-associated solid tumors usually develop after a considerably longer latency period (at least 5-9 years) as measured from primary therapy of HD, with elevated risks persisting for at least 3 decades. The majority of these solid tumors arise within or at the edges of prior HD radiotherapy fields, supporting the case for antecedent radiation contributing to tumor occurrence. Recent studies have also documented a breast cancer risk increased significantly with increasing radiation dose to reach 8-fold for the highest category (median dose 42 Gy) compared to the lowest dose group.


Terry Dagradi

"I can still recall a survivor friend telling me that I might not have the luxury of returning to who I once was because that person never had cancer. I soon realized that survivorship was very complex and that I would need considerable support from my family and friends as I created my 'new normal.' "

–Peter Lamothe / Hamden, CT

In a British survey of 1,693 HD patients given chemotherapy only, the relative risk of lung cancer was significantly increased 3-fold.

Cognitive Dysfunction: "Chemobrain" or "Chemofog"

(Adapted from *Medical and Psychosocial Care of the Cancer Survivor,* Jones and Bartlett, *In Press*)

Cara Miller, B.S., Graduate Fellow, Gallaudet University, Dept. of Clinical Psychology

In the Words of a Cancer Survivor…

> My mental stamina is limited, and if I do too much I feel exhausted and need to rest. I used to be good at multitasking, but now I need to focus all of my energies on doing one task at a time. At its worst, I would describe the feeling I have as "shredded cardboard" in my brain.
>
> **—Barbara, a 65-year-old breast cancer survivor who received chemotherapy**

Cognitive changes associated with chemotherapy are not uncommon. In fact, a reported 20% to 30% of cancer patients report symptoms of chemotherapy-induced neurocognitive impairment—"chemobrain" or "chemofog," as it is sometimes colloquially termed. Estimates of female breast cancer patients who experience this condition are range from 16% to 40%.

Symptoms of cognitive changes induced by chemotherapy were first reported by female breast cancer patients complaining of problems with word finding, memory, multitasking, learning, processing speed, attention, concentration, language, and judging spaces and layout. Previously, doctors assumed that cognitive changes were the byproduct of other chemotherapy side effects such as anemia, fatigue, and depression. This assumption, coupled with the fact that cognitive impairment may manifest differently in many cancer patients, has frequently resulted in underreporting of cognitive changes. For some, cognitive changes are a temporary "mild annoyance," while for others, the long-lasting debilitating condition may prevent return to work and return to normal functioning.

In 1998, Schagen and colleagues examined breast cancer patients treated with chemotherapy and compared this group with a control group of breast cancer patients who had been treated with surgery and radiation therapy. The chemotherapy patients reported significantly more problems than control patients in regard to concentration (31% vs 6%) and memory (21% vs 3%). However, no relationship was found between patients' reported complaints of cognitive impairment and their results on neuropsychological tests. Instead, tests indicated that 28% of chemotherapy patients displayed symptoms of cognitive functioning compared to 12% of the control patient group. Ahles found that cancer patients treated with chemotherapy scored significantly lower on standardized tests measuring mental and psychological functions than those who had only local therapy. Their scores were lower on average whether or not patients reported having depression, anxiety, or fatigue, indicating that the lower scores resulted from cognitive impairment due to chemotherapy.

Some pharmacologic approaches can be suggested, but primarily a behavioral approach has been suggested as a first form of remediation. For many patients, the neurocognitive changes gradually improve over time, and so strategies to compensate for the temporary deficits can be helpful. As suggested by the Mayo Clinic, these include:

- Decrease workload
- Avoid multiple tasks
- Prepare for tomorrow today
- Make lists
- Increase sleep
- Use mnemonics and wordplay
- Use electronic calendars to record appointments
- Use key chains that beep when pressed
- Color-code and label items
- Track memory problems in small diaries
- Play crossword puzzles and Sudoku squares
- Try systematic computer training

Post Traumatic Stress

(Adapted from *Medical and Psychosocial Care of the Cancer Survivor,* Jones and Bartlett, *In Press*)
Mitch Golant, PhD, Vice President, The Wellness Community

Distress is a prevalent reaction to cancer. The most commonly reported responses to traumatic events were intrusive thoughts and avoidance. Intrusion may be experienced as nightmares about death, anxious thoughts as an anniversary of diagnosis approaches, overwhelming fear of recurrence etc. Intrusion may include overwhelming and invasive thoughts that interrupt normal thought processes. Adaptively, avoidance becomes a coping strategy to manage the intrusive thought. Intrusive thoughts represent an attempt to integrate the traumatic experience in order to achieve a sense of completion, resolution, and/or understanding. Thus, intrusion and avoidance represent not only emotional distress, but also incomplete cognitive processing.

Distress, defined as an unpleasant emotional experience that can impact cognitive, behavioral, social, emotional and spiritual functioning, is a common reaction among people with cancer. Distress may interfere with the ability to cope effectively with the physical symptoms of the illness and/or impact the likelihood of a patient receiving treatment. Symptoms of distress include a wide spectrum of feelings ranging from sadness, fear, anger and unhappiness to severe depression, panic and debilitating anxiety.

Theoretically, diminishing distress may be achieved by reconciling one's previously-held worldview with the cancer diagnosis through cognitive integration. Moreover, there are two categories of cognitive integration: assimilation and accommodation. Assimilation is a reappraising of the traumatic events in order to make them fit one's worldview or preconceptions of life. Accommodation is adjusting mental models to fit the traumatic situation.

Social interactions play a crucial role in the success or failure of cognitive integration and completion. Social support can be defined as positive, affirmative and empathetic social interactions. However, social constraints on disclosure are unsupportive social interactions that discourage talking about a stressful event.

Family members may feel threatened and distance themselves from their loved one with cancer. These situations discourage emotional expression. In effect, constraint on disclosure leads to emotional suppression which may prevent effective cognitive processing of the trauma associated with cancer and thereby prolong psychological distress.

If families or friends are unable to provide the much needed emotional support for people with cancer, then professionally-facilitated support groups play a crucial role providing a safe environment to express emotions by being with others who are going through what they are experiencing. Support groups encourage confronting, contemplating and re-evaluating traumatic event and may counter social constraint encountered in other relationships, thereby facilitating emotional assimilation and accommodation. Effective support groups also create a forum for safe expression of emotions.

Finding Benefits in the Cancer Experience

(Adapted from *Medical and Psychosocial Care of the Cancer Survivor,* Jones and Bartlett, *In Press*)

Heather Jim, PhD and Paul Jacobsen, PhD

Most survivors are able to point to benefits in one or more areas of life as the result of cancer. Evidence suggests that the fear, uncertainty, and loss wrought by cancer often spur a search for deeper meaning and a fresh perspective on old problems. As a result, survivors frequently report that life after diagnosis is characterized by a richness and depth that was previously lacking. Benefit-finding in individuals diagnosed with cancer begins with a theoretical overview of cancer as a traumatic experience, then defines and describes benefit-finding.

As a potentially life-threatening illness, cancer can be conceptualized as a traumatic life event. Although post-traumatic stress disorder due to cancer diagnosis and treatment is relatively uncommon, it is not unusual for patients to report some symptoms of traumatic stress, particularly at diagnosis. These symptoms commonly include intrusive thoughts about the cancer and efforts to avoid reminders of the disease. A cancer diagnosis may seem unfair, unpredictable, and entirely out of one's control. Consequently, the patient must reconcile their disease with previous assumptions about life. They must either build a new series of assumptions to accommodate the reality of their disease or change the meaning of the cancer to maintain positive assumptions about the world and themselves.

Benefit-finding is an effort to change the meaning of cancer to maintain previous positive assumptions. It refers to the reinterpretation of cancer as an opportunity for personal growth. Benefit-finding occurs as the result of the question, "What has the experience taught me about myself and about my relationships with others in my life?" Benefits represent something new and positive that is believed to surpass what was present before diagnosis. Survivors commonly report benefits in three specific domains of life: enhanced social resources, enhanced personal resources, and improved coping skills.

Survivors commonly attribute benefits to the cancer experience, including enhanced social resources, enhanced personal resources, and improved coping skills. Benefits are more likely to be reported by survivors who are younger, members of racial/ethnic minority groups, have more severe disease, and undergo more aggressive treatment regimens. Longer time since diagnosis and engaged coping strategies are also associated with greater benefits. The question of whether benefit-finding represents actual change or motivated illusion is in some ways unimportant. If survivors believe that benefit-finding strengthens fragile hope, offers a sense of meaning, and makes the destruction wreaked by cancer seem more manageable then it is valuable. This is the intuitive appeal of benefit-finding and perhaps the reason that benefit-finding interventions have been created absent solid evidence that it is associated with psychological adjustment. Clinicians would do well to take a moderate approach to benefit-finding, neither rejecting reported benefits nor insisting on a rosy interpretation of the cancer experience. Clinicians should acknowledge benefits reported by patients but not convey the impression that survivors should find benefits. Survivors must ultimately decide for themselves whether cancer has resulted in positive changes in their lives.

Sexual Problems for Cancer Survivors

(Adapted from *Medical and Psychosocial Care of the Cancer Survivor,* Jones and Bartlett, *In Press*)

Leslie R. Schover, PhD, MD Anderson Cancer Center

Currently in the United States, 50% of our approximately 10 million cancer survivors have had breast, prostate, gynecological, or colorectal malignancies. At least half of these 5 million men and women suffer from long-term, severe sexual dysfunction that is directly related to their cancer treatment. The most common problems include loss of sexual desire for men and women, erectile dysfunction in men, and vaginal dryness, tightness, and pain with sex in women. Although a number of recent studies have demonstrated good results for short-term psychoeducational interventions, most cancer survivors do not have access to expert, multidisciplinary care for their sexual problems.

Since most problems involve an organic deficit as well as the emotional impact of the sexual dysfunction, optimal programs combine gynecologic or urologic consultation with counseling by a mental health professional trained in both psycho-oncology and sex therapy. Unfortunately, such treatment programs may not be well-reimbursed by private insurers, particularly for the time-consuming mental health services. It is difficult for survivors to find knowledgeable practitioners outside of major cancer centers or urban areas, and true, multidisciplinary clinics that treat cancer-related sexual dysfunction are extremely rare. Also, few men or women seek help for sexual dysfunction.

Our own attempt to provide a short-term, comprehensive psychoeducational intervention for sexual dysfunction after prostate cancer has shown significant increases, at least in the short-term, in sexual satisfaction for both partners and in the percentage of men utilizing a medical treatment for ED. The intervention included partners and focused on enhancing sexual communication and expression of affection in the couple, coping with menopausal symptoms for women, partners' agreeing on a medical treatment for ED, and trouble-shooting in incorporating new treatments into the couple's sexual routine.

Only a few researchers have tried to intervene to improve sexual function in women after cancer. A Canadian group used support and education to try to increase adherence to vaginal dilation, with some improvement in dilator usage, mainly for younger women. A three-session peer counseling intervention based on a written workbook had similar results for a cohort of African-American breast cancer survivors. A pilot psychoeducational program with handouts and three sessions of counseling by a psychologist helped improve sexual function in survivors of early-stage gynecological cancer. Giving women accurate knowledge about sexual anatomy, function, and the impact of cancer treatment is crucial in these programs. Empowering women to ask to have their sexual needs met with a partner is also an important element, as is overcoming fears that having cancer will decrease a woman's sexual attractiveness to her partner.

Paying Attention to "Co-Survivors:" Family and Caregivers

(Adapted from *Medical and Psychosocial Care of the Cancer Survivor,* Jones and Bartlett, *In Press*)

Mitch Golant, PhD, Vice President, The Wellness Community

Caregiving is stressful. Diminishment in the patient's functional ability, organ function, appearance, career, family and social role and self-image directly impact the caregiver. During the initial or acute phase, the caregiver(s) and patient are under siege. They are active as a unit to adjust to the diagnosis. The chronic phase follows. Primary treatment has been administered and the patient is dismissed from the hospital. Caregivers are left to take on additional responsibilities; some are complex and others may be simple but tedious. The final phase is resolution, when the family must begin the survivorship or bereavement process.

Too often caregivers don't find outlets to express anxieties and instead emotions are suppressed and can create a divide or resentment towards the loved one with cancer.

A study showed that while patient distress did diminish over time, that of the caregiver did not. Long-term caregivers suffer from impaired immunity for as long as three years after their caregiving role ended, suggesting that people who care for those with chronic illnesses such as cancer, are at an increased risk for developing their own serious health problems.

"In October 2006, our wife/mother Tama was diagnosed with colorectal cancer at age 48 with no family history. She set a great example for all as she underwent chemo, radiation and surgery in the ensuing months with the related discomforts. We have always been a close family, but this experience has made us appreciate every day life even more."

–**John Andres / Fairfield, CT**

Eight in ten cancer patients/survivors and caregivers agree that patients were able to focus on their treatment because their caregiver provided emotional support, provided transportation, prepared meals, performed household chores, provided financial assistance, and managed finances. However, these additional responsibilities are taxing on the caregiver's own well-being. Nearly half of cancer patients and survivors believe their caretakers felt regular distress during their cancer experience (49%). In stark contrast, 80% caregivers say they personally experienced regular distress throughout the cancer experience.

This extra distress often leads to burnout—with symptoms headaches, insomnia, backaches, lethargy, lingering colds, gastrointestinal upsets, or cardiovascular problems—and is signaled by emotional components as well, including frustration, anger, insecurity, resentment, and depression. It's critical that caregivers understand that while managing their own stress may seem secondary to the immediate needs of their loved one with cancer, at some point, they must make their own well-being a priority. Before a caregiver can be helpful to their loved ones, they need to know how to cope with their own stress.

"As cure becomes the rule rather than the exception, we must strive to restore our patients to health as well as life."

Nina Kadan-Lottick, MD, MSPH
Director, HEROS Clinic,
Yale University

What is a childhood cancer survivor?

The National Cancer Institute defines a cancer survivor as any person diagnosed with cancer from the day of diagnosis to highlight that quality of life should be emphasized from the beginning of treatment. However, most clinicians conceptualize cancer survivorship care as applying to the period beginning after primary cancer therapy and the associated acute toxicity effects are past.

Why is childhood cancer survivor care important?

Currently, about 80% of children diagnosed with a cancer will be cured of their cancer. Unfortunately, about 70% of survivors will experience at least one adverse medical, neurocognitive, or psychosocial outcome. About 40% of survivors will develop two or more treatment-related conditions. Examples of some of these late effects include subsequent cancers, cardiomyopathy, pulmonary fibrosis, early menopause, infertility, problems with memory, and post-traumatic stress disorder. Currently survivors are about 10 times more likely to have early mortality than individuals of similar age and gender in the general population.

Therefore, childhood cancer has become transformed into a chronic disease rather than just an acute illness. Fortunately, most late effects of therapy are amenable to early screening and intervention. So with the right care, survivors have better outcomes.

How many childhood cancer survivors are there?

About ten years ago, the Institute of Medicine estimated that there are 270,000 childhood cancer survivors in the United States. Since then, the number has continued to increase because cure rates have increased since then. It is estimated that currently about 1 in 500 young adults between 20 and 39 years is a survivor of childhood cancer. On average, every family practitioner and internist has about 5 survivors in his/her patient population.

Are all survivors at risk for the same late effects?

A patient's risk of a late effect is associated with his/her specific cumulative chemotherapy, radiation, and surgery exposures. Therefore, follow-up screening needs to be individualized to the actual treatment exposures. Factors such as age and gender can moderate certain late effects. For example, there is a higher risk of cardiomyopathy after anthracycline chemotherapy in females and those treated at younger ages. The cumulative incidence of cardiomyopathy continues to increase for decades after the anthracycline exposure. In contrast, the risk of subsequent leukemia peaks about 10 years treatment with alkylating agents. Some patients were treated with therapies associated with little or no late effects. Other individuals may not have received toxic therapy, but have a positive cancer family history that requires vigilance for other cancers. Because of the variability in risk, it is critical to know a patient's treatment history and cancer family history to design the optimal follow-up plan.

What are some examples of late effects that survivors can develop?

Depending on the previous treatment exposures, almost every organ system can be potentially affected by the previous cancer therapy. The following table gives some common types of adverse late outcomes observed in patients treated for different cancers from the Institute of Medicine., *Childhood Cancer Survivorship: Improving Care and Quality of Life.* 2004, Washington, D.C.: National Academies Press.

Table 2 Common Types of Adverse Late Outcomes

Cancer	Potential Late Effects
Leukemias	■ Cognitive effects (e.g., learning disabilities) ■ Abnormal growth and maturation ■ Heart problems ■ Second cancers ■ Hepatitis C (effects of blood transfusion) ■ Weakness, fatigue ■ Obesity ■ Osteoporosis ■ Avascular necrosis of bone ■ Dental problems
Brain cancer	■ Neurologic and cognitive effects (e.g., learning disabilities) ■ Abnormal growth and maturation ■ Hearing loss ■ Kidney damage ■ Hepatitis C ■ Infertility ■ Vision problems ■ Second cancers
Hodgkin's disease	■ Adhesions and intestinal obstruction (if spleen removed) ■ Decreased resistance to infection (potential for life-threatening sepsis) ■ Abnormal growth and maturation ■ Hypothyroidism (effect of neck radiation) ■ Salivary gland malfunctioning (effect of jawbone irradiation) ■ Lung damage ■ Heart problems ■ Infertility ■ Hepatitis C ■ Second cancers (e.g., breast cancer in females)
Non-Hodgkin's lymphoma	■ Heart problems ■ Hepatitis C ■ Cognitive effects ■ Infertility ■ Osteopenia/osteoporosis

continued on next page >

> *Table 2* *continued from previous page*

Cancer	Potential Late Effects
Bone tumor	■ Amputation/disfigurement ■ Functional, activity limitations ■ Damage to soft tissues and underlying bones (radiation may cause scarring, swelling, or inhibit growth) ■ Heart problems ■ Hearing loss ■ Kidney damage ■ Second cancers ■ Hepatitis C ■ Fertility problems
Wilm's tumor	■ Heart problems ■ Kidney damage ■ Damage to soft tissues and underlying bones (radiation may cause scarring, swelling, or inhibit growth) ■ Second cancers ■ Fertility problems ■ Scoliosis
Neuroblastoma	■ Heart problems ■ Damage to soft tissues and underlying bones (radiation may cause scarring, swelling, or inhibit growth) ■ Neurocognitive effects ■ Hearing loss ■ Hepatitis C ■ Second cancers ■ Kidney damage
Soft tissue sarcoma	■ Amputation/disfigurement ■ Functional, activity limitations ■ Heart problems ■ Damage to soft tissues and underlying bones (radiation may cause scarring, swelling, or inhibit growth) ■ Second cancers ■ Hepatitis C ■ Kidney damage ■ Cataracts ■ Infertility ■ Neurocognitive effects

What is meant by *survivorship care?*

The Institute of Medicine has set forth policy statements stating that all individuals previously treated for childhood cancer should receive at least the following:

1) **A treatment summary** with details regarding chemotherapy, dosages and sites of radiation therapy, and past surgical procedures.
2) **Life-long individualized follow-up care** consisting of screening and early intervention for health conditions associated with a patient's specific previous therapy and family cancer history, if relevant.
3) **Education** about desirable lifestyle and health behaviors to minimize risk of adverse outcomes.

What are some of the challenges of taking care of childhood cancer survivors?

Survivors are diagnosed and treated as children and often do not recall important details about their past cancer and treatment. One study concluded that a significant proportion of adult survivors of childhood cancer did not even know the name of their previous cancer. They could not recall with high accuracy rates whether they had radiation therapy or splenectomy. Sometimes, it is impossible to determine past cancer therapy exposures because the relevant medical records are no longer available. This lack of knowledge also means that most survivors are not aware that they need extra health screening.

Many of the conditions that survivors develop are clinically silent for a long period of the disease process. Examples of such conditions include early stages of subsequent breast cancer, thyroid hormone deficiency, and cardiomyopathy. Therefore, specific screening tests are needed to detect these conditions before they progress.

Childhood cancer survivors often are complex and time-consuming. Many primary care doctors may feel that they do not have the expertise in survivorship issues to provide the needed care. Free web-based follow-up care recommendations are available now (see next page) and more interactive tools are being developed.

Why do survivors need lifelong survivorship care?

Survivorships are at risk for different outcomes at different ages. The following are some key outcomes to monitor in by sub-groups of survivors at different ages:

- Trouble with school work because of slowed processing speed, decreased focus, and impaired memory after chemotherapy or cranial radiation.
- Short stature because of growth hormone deficiency that requires growth hormone replacement during childhood before the growth plates close.
- Bone mineral density monitoring in patients with gonadotoxic therapy and history of steroid therapy, starting in childhood.
- Lifelong echocardiogram monitoring for cardiomyopathy after exposure to chest radiation and/or anthracycline chemotherapy.
- Yearly MRI's to screen for breast cancer after chest radiation, beginning eight years after radiation or at age 25 years.
- Need for estrogen replacement in young woman with premature menopause.
- Sperm analysis in 35 year-old man who is newly engaged and wants to know his fertility status after receiving alkylating agents as an adolescent.
- A 45 year-old man with a stroke after head and neck radiation.

Step-by-step survivorship care: one approach for the primary care doctor

1) Be aware of who the childhood cancer survivors are in your practice. For new patients, ask specifically about past history of cancer therapy.

2) Request medical records from the oncology treatment physician or clinic. Ideally, the patient should request that the treating oncologist prepare a succinct list of the previous chemotherapy agents, sites and doses of radiation, surgeries, and/or stem cell transplant.
   a. For most of the chemotherapy agents, just the names are adequate and the doses are not needed.
   b. The exceptions are anthracyclines (doxorubicin, daunorubicin, idarubicin) and alkylating agents (e.g. cyclophosphamide, procarbazine, etc.). Cumulative doses of anthracycline are an indication of cardiomyopathy risk and how frequently screening echocardiograms should be done. Cumulative alkylating agent doses give an indication of fertility potential.

You then have the choice of going to step 3 or step 4, depending on the patient and your resources.

3) Using the Children's Oncology Group Long-Term Follow-up Guidelines, which are consensus recommendations on preventive care for childhood cancer survivors, you can create a follow-up schedule of screening tests: www.survivorshipguidelines.org.

   The guidelines are organized by treatment exposure. You can look up the recommended screening for each of the treatment exposures. In this way, you could compose a lifetime follow-up plan for your patient. This may be a particularly good strategy for more straight forward patients and those who are reluctant to go back to a cancer center.

4) Alternatively, you can refer your patient to HEROS Clinic. We will request the cancer treatment records, compose the treatment summary, and design an individualized follow-up care plan. We also would then do the initial evaluation and send you a summary of our evaluation as well as the lifetime follow-up care plan.

5) The individualized follow-up care plan would then be incorporated into the other services provided by the primary care physician. HEROS Clinic would be available by phone or email for complications. We could also evaluate the patient in our clinic again, if preferred.

THE HEROS CLINIC VISIT

- History and physical and "summing up" conference with HEROS Medical Director, Dr. Kadan-Lottick
- Individualized battery of screening blood tests and radiology studies
- Endocrinology evaluation for growth failure, hypogonadism, precocious puberty, and hypothalamic-pituitary dysfunction
- Neuropsychologist screening for cognitive impairment and affective disorders
- Health education by nurse for desirable diet and lifestyle behaviors as well as survivor issues specific to patient
- Referral to sub-specialty services identified as areas of need at the HEROS visit
- The opportunity to participate in survivorship observational and interventional trials if patient eligible and interested
- Written treatment summary, active problem list, and individualized plan for survivor follow up care that is mailed to the patient, the primary care doctor, and all other health care providers who share in the patient's care.

Strategies for billing for survivorship visits

- Bill for the outcome condition(s) as the primary diagnoses; the original cancer should be one of the subsidiary diagnoses.

  Example: *In a 26 year-old patient with a history of Hodgkin disease who has hypothyroidism as a result of mantle radiation and hypogonadism secondary to alkylating agents, billing diagnoses should be: 1) hypothyroidism, 2) ovarian insufficiency, 3) Hodgkin disease.*

- For complex patients requiring coordination of services before and after the clinic visit, bill for "medical conference" as a way to acknowledge the medical expertise/planning.

What does the future hold for childhood cancer survivors?

These brave heroes courageously fought cancer and won. As cure becomes the rule rather than the exception, we must strive to restore our patients to health as well as life. We do not know yet the ideal model for delivering high quality survivor care, but all acknowledge that primary care doctors are best positioned to really make a difference.

Acknowledgements

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References and Selected Readings

This manual contains significant amounts of materials that have been adapted or excerpted from *Medical and Psychosocial Care of the Cancer Survivor*, Boston, MA.

Jones and Bartlett, 2009. *In Press*. We wish to thank the publisher for permission to use this material.

The book, *Medical and Psychosocial Care of the Cancer Survivor* contains specific references that credit the primary sources. This manual does not contain these references and the reader is asked to refer to the book for proper credits and to a link that will be provided on the CT Challenge website.

To obtain a copy of *Medical and Psychosocial Care of the Cancer Survivor,* please contact:

Jones and Bartlett Publishers, Inc.
40 Tall Pine Drive
Sudbury, MA 01776
E-mail: info@jbpub.com
1-800-832-0034

In this manual "Seasons of Survivorship" is excerpted from *The Cancer Journal*, Cancer J. 2008 Nov-Dec;14(6) with permission from Lippincott. We are thankful to them for allowing us to use this chapter. The references are found in *The Cancer Journal*.

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SAMPLE

[INSTITUTION]
CANCER TREATMENT SUMMARY AND TRANSITION PLAN
[FIRST NAME] [LAST NAME]

Date of Birth: [DATE OF BIRTH]
[INSTITUTION] MRN: [MRN]

This is your ***Transition Plan*** which should be shared with your doctor(s) and kept in your personal files.

TREATMENT SUMMARY
[IN CHRONOLOGICAL ORDER]

Date of Dx	***Diagnosis***	***Stage***	***Occur rence***	***Primary Site***	***Age at Dx***	***Protocol***	***Cycles***
2/1/07	Breast Cancer	2	First	L Breast	45	AC	4

Primary Tumor	***Regional Lymph Nodes***	***Distant Metastasis***	***Histopathologic Grade***	***ER***	***PR***	***Her2/ neu***
2.4cm T2	N0	M0	2	Pos.	Pos.	Neg.

Lymphovascular Invasion (LVI): YES/NO   No

Treating Institution: Dana Farber Cancer Institute

SUMMARY OF PRESENTATION

[NAME] NOTED A MASS IN HER LEFT BREAST IN JAN 2007. MAMMOGRAM CONFIRMED A 2.5 CM MASS WITH MICROCALCIFICATIONS. CORE BX CONFIRMEDTHE DIAGNOSIS FOLLOWED BY A LUMPECTOMY AND SENTINAL NODE BX.

SYSTEMIC THERAPY

- Ac X 4 CYCLES. Dose dense

RADIATION (DOES NOT INCLUDE TRANSPLANT CONDITIONING)

- 6200 cGy to left breast with boost to bx. site

SURGERY (DOES NOT INCLUDE TRANSPLANT CONDITIONING)

- Left Breast core biopsy
- Left Breast Lumpectomy and node sampling.

TRANSPLANT

Treatment Completion Date: 7/1/07

ONCOLOGY FOLLOW UP

YOU HAVE COMPLETED TREATMENT WITH CHEMOTHERAPY AND RADIATION THERAPY AND NOW ARE IN REMISSION. BELOW ARE RECOMMENDATIONS FROM YOUR PHYSICIAN AND MEDICAL TEAM.

Symptoms of Concern:
Now treatment is complete, there are some symptoms of concern. Please call Dr. Donald Smith (617)632-3000) if you experience any of these symptoms; fever, shortness of breath, persistant cough, bone pain. These symptoms can also be signs of other illnesses.

[INSTITUTION]
CANCER TREATMENT SUMMARY AND TRANSITION PLAN
[FIRST NAME] [LAST NAME]

SAMPLE

Date of Birth: [DATE OF BIRTH]
[INSTITUTION] MRN: [MRN]

Clinic Visits and Tests

CLINIC VISITS	
TYPE	FREQUENCY
Dr. Smith	Office Visit Every 3 months for one year then every four months in year two.

IMAGING	
TYPE	FREQUENCY
Mammogram	In 6 months from now and then yearly.

LABORATORY WORK	
TYPE	FREQUENCY
Blood Work	When you see Dr. Smith

VACCINES	
TYPE	STATUS
Flu Vaccine	Yearly

Medication – Tamoxifen 20mg every day

Care Team

Primary Oncologist	Dr. Donald Smith	(617)632-3000
Nurse Practitioner	Debbie Clark, APRN	(617) 632-3000
Psycho-social Provider	Amy Grose, M.S.W.	(617)632-3112
Primary Care Provider	David Rosenberg, M.D.	(617)774-6111

These guidelines do not replace the expertise and clinical judgment of your physician, who is familiar with your situation, medical history, and personal preferences. Each patient's situation must be evaluated individually at each follow up visit.

General recommendations for all cancer survivors include:

- ✓ Annual physical examinations with primary care provider
- ✓ At least, yearly dental examinations
- ✓ Annual influenza vaccine
- ✓ Dental examination every 6 months

The Connecticut Challenge serves cancer survivors, creating special survivorship clinics and funding research into issues survivors face after treatments end.

We Ride

BECAUSE CANCER SURVIVORS NEED FOLLOW-UP CARE FOR LIFE

You Can Help

DONATE

Please remember the CT Challenge in your year-end giving plans

RIDE OR VOLUNTEER

Mark your calendar to be in Fairfield on Saturday, July 25th, 2009

You can do it all at

ctchallenge.org

Join our group on Facebook

Search "Connecticut Challenge"

CONNECTICUT **challenge**

Cycling for Cancer Survivors

Get More Online!

The Connecticut Challenge is extending valuable resources to cancer survivors and medical professionals through its website at ctchallenge.org. As a professional you will be able to view the following:

- → A soft copy of this document and supporting documents
- → Our video series on a variety of survivor ship topics including our 2009 Symposium
- → Important articles and research papers about cancer survivorship
- → Worldwide cancer survivorship news feeds
- → Information on Connecticut Challenge programs and research grants available for medical professionals, hospitals and community organizations
- → Connecticut Challenge event listings
- → Resources and information for your patients (coming soon)

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www.ctchallenge.org

Bike Across America Inc. is a registered 501(c)(3) public charity doing business as The Connecticut Challenge. The organization raises funds to advance cancer survivorship care and resources through health services, patient education, research and its provider network programs across Connecticut.

CONNECTICUT challenge For Cancer Survivors