

Comprehensive Survivorship Services

A practical guide for community cancer centers

A Publication of the Association of Community Cancer Centers

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give her  for efficacy

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15.5% vs 8.4%

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(albumin-bound)

BOUND AND DETERMINED

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ABRAXANE therapy should not be administered to patients with metastatic breast cancer who have baseline neutrophil counts of less than 1,500 cells/mm³. In order to monitor the occurrence of bone marrow suppression, primarily neutropenia, which may be severe and result in infection, it is recommended that frequent peripheral blood cell counts be performed on all patients receiving ABRAXANE.

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The use of ABRAXANE has not been studied in patients with hepatic or renal dysfunction. In the randomized controlled trial, patients were excluded for baseline serum bilirubin >1.5 mg/dL or baseline serum creatinine >2 mg/dL.

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ABRAXANE contains albumin (human), a derivative of human blood.

Caution should be exercised when administering ABRAXANE concomitantly with known substrates or inhibitors of CYP2C8 and CYP3A4.

ABRAXANE therapy should not be administered to patients with metastatic breast cancer who have baseline neutrophil counts of less than 1,500 cells/mm³. It is recommended that frequent peripheral blood cell counts be performed on all patients receiving ABRAXANE. Patients should not be retreated with subsequent cycles of ABRAXANE until neutrophils recover to a level >1,500 cells/mm³ and platelets recover to a level >100,000 cells/mm³.

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Sensory neuropathy occurs frequently with ABRAXANE. The occurrence of grade 1 or 2 sensory neuropathy does not generally require dose modification. If grade 3 sensory neuropathy develops, treatment should be withheld until resolution to grade 1 or 2 followed by a dose reduction for all subsequent courses of ABRAXANE.

It is recommended that nursing be discontinued when receiving ABRAXANE therapy.

Severe cardiovascular events possibly related to single-agent ABRAXANE occurred in approximately 3% of patients in the randomized trial. These events included chest pain, cardiac arrest, supraventricular tachycardia, edema, thrombosis, pulmonary thromboembolism, pulmonary embolism, and hypertension.

To learn more about ABRAXANE, visit our Web site at www.abraxane.com

Please see Brief Prescribing Information on the following page.

Reference: 1. ABRAXANE [prescribing information]. Los Angeles, Calif: Abraxis Oncology, a Division of Abraxis BioScience, Inc.; May 2007.

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PHOTOGRAPH COURTESY OF THE ENH LIFE PROGRAM.

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Artwork (above and below) courtesy of The Center for Cancer Care at Exeter Hospital. These works were created by participants in the cancer center's Wellness Program. See page S21 for more.



ARTWORK ON FRONT COVER, PAGES S4, S5, S7, AND BACK COVER COURTESY OF THE CENTER FOR CANCER CARE AT EXETER HOSPITAL. THESE WORKS WERE CREATED BY PARTICIPANTS IN THE CANCER CENTER'S WELLNESS PROGRAM. SEE PAGE S21 FOR MORE.

A Prescription for the Rest of One's Life

by Richard B. Reiling, MD, FACS

The focus of my ACCC presidency (2007-2008) has been survivorship. Cancer survivorship is not a new concept to cancer patients or to oncology care providers. However, the process of providing comprehensive survivorship programs is new. The Institute of Medicine's (IOM) recent report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, set out both the problems and the challenges we face as we strive to provide the support and services our survivors want and need.

In my President's Message column for *Oncology Issues*, I have written about a survivor's need for "A Prescription for the Rest of One's Life." As both an oncology surgeon and a cancer survivor myself, I view the need from both perspectives. And as a cancer survivor looking forward to the rest of my life, I am mindful that survivorship encompasses more than just the cancer patient and his or her healthcare providers—it involves the patients' family, friends, and caretakers, as well.

With this special supplement on Survivorship, ACCC brings together practical resources and tools to help community oncology programs respond to the need for comprehensive survivorship services. Included are ACCC's Cancer Program Guidelines new section on "Survivorship Services," which outline optimal survivorship components within a comprehensive cancer program.

As the model programs described in this supplement make clear, innovative survivorship efforts are already underway at ACCC member institutions—ranging from small community hospitals to large community health systems.

Currently, there are 12 million cancer survivors in the United States. Unfortunately, almost all of us will either be a survivor of cancer or closely related to a loved one with cancer. ACCC is committed to serving as a resource for helping all of its member facilities to develop comprehensive survivorship programs. We trust that this supplement will be the springboard for providing your center the tools to help you do just that.



The art becomes a valuable tool with which to enter the unconscious, to express what words often cannot.

—Lori Nathan, ATR
Art Therapist at the Center for
Cancer Care at Exeter Hospital
(See page S21 for more.)

The Association of Community Cancer Centers (ACCC) and its editorial staff would like to thank Guest Editor, Virginia T. Vaitones, MSW, OSW-C, who provided expert guidance in the development of this tool. With more than 30 years of experience as an oncology social worker, Ms. Vaitones has also been an active participant and supporter of ACCC, serving on the Association's Board of Trustees, and ACCC's Program, Guidelines, and Patient Advocacy Committees. ACCC would also like to thank AstraZeneca and Abraxis Oncology for sponsoring the development and dissemination of this publication.

ACCC's Cancer Program Guidelines 2008

Survivorship Services: Chapter 4, Section 16

The Association of Community Cancer Centers (ACCC) Board of Trustees recently approved ACCC's *Cancer Program Guidelines 2008*, which features a new Survivorship Services section. The revised guidelines state that "an optimal comprehensive cancer program should make available information and programs specific to survivorship issues to cancer patients and their families."

Cancer survivorship—a key component of comprehensive care—has been a key ACCC focus issue in 2007-2008. Survivorship has figured prominently in ACCC's two annual national meetings. This special supplement, "Comprehensive Survivorship Services: A Practical Guide for Community Cancer Centers," in *Oncology Issues* as well as publication and distribution of ACCC's *Cancer Program Guidelines 2008* are part of the 2007-2008 Presidential Grant, sponsored by AstraZeneca, LP, and Abraxis Oncology.

We hope you'll share ACCC's *Cancer Program Guidelines 2008*, and particularly its Survivorship Services section, with your cancer care team. The entire document is available online at ACCC's website: www.accc-cancer.org.

ACCC's *Cancer Program Guidelines 2008* have been established to assist cancer programs that

want to develop and/or maintain a comprehensive interdisciplinary program that meets the needs of cancer patients and their families. These guidelines were developed to reflect the optimal components for a cancer program. ACCC's guidelines are not intended to act as an accrediting or credentialing mechanism and are not a list of standards, such as those published by the American College of Surgeons Commission on Cancer. Guidelines should not be a surrogate for independent medical judgment; they serve only as the term implies: as guidelines to help programs meet the optimal attributes.

Suggestions and comments for future additions to ACCC's Cancer Program Guidelines are welcome. You can email us at info@acc-cancer.org.

Sincerely,

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Chair, ACCC Committee for Program Guidelines

Virginia T. Vaitones, MSW, OSW-C
Member, ACCC Committee for Program Guidelines

Patricia A. Spencer-Cisek, MS, APRN-BC, AOCN
Chair, ACCC Patient Advocacy Committee

Survivorship Services

Guideline 1: Information and programs specific to survivorship issues are available to cancer patients and their families.

Rationale

Survivorship is defined as the experience of living with, through, and beyond cancer for both patients and the people in their lives who are impacted by the diagnosis. It comprises the physical, psychological, emotional, social, spiritual, and economic aspects of life that may be influenced by cancer at any time from diagnosis through treatment and all remaining years of life.

Characteristics

A. Programs and educational resources for survivors and their families should include but are not limited to the following:

1. A written cancer treatment summary and follow-up care plan that would include a summary of the cancer treatment, recommended follow-up for cancer surveillance, late and long-term effects of their disease and its treatment(s), symptom management, as well as psychosocial, spiritual, and financial concerns. Access to information about cancer prevention, early detection, genetics, disease treatment, symptom management and psychosocial, spiritual, financial concerns through written materials and/or referrals via the Internet, other

- experts, or support organizations
2. Information about local, regional, and national resources on survivorship and survivorship research via written materials and/or referrals through the Internet, other experts, or support organizations for any aspect of their cancer, cancer care, research, advocacy, and survivorship
3. Access to support groups either on-site or by referrals to local or web-based support groups and other support mechanisms, such as telephone connection programs linking survivors together
4. Information about specific survivorship issues, such as employment rights, insurance coverage, late and long-term effects of disease and treatment, advance directives, living will and durable power of attorney, estate planning, options for recurrent disease management, and end-of-life care planning
5. Programmatic opportunities to participate with the care team to develop community outreach education and support programs for quality cancer care in the community and to educate professional staff about the cancer experience.

B. Resources are allocated to provide a robust survivorship program.

C. National standards for survivorship will be incorporated into program planning, implementation, and evaluation.

Survivorship: A Psychosocial Perspective

A conversation with Brad Zebrack, PhD

Brad Zebrack, PhD, is assistant professor at the University of Southern California School of Social Work. His teaching and research interests are in the area of health, medicine, and quality of life, with a particular focus on the impact of cancer on patients, survivors, and their families. A long-term survivor of Hodgkin's disease, Dr. Zebrack currently serves on the board of directors for the American Psychosocial Oncology Society and the Association of Oncology Social Work, for which he chairs the Social Workers in Oncology Research Group.

Q. *A surgical oncologist and cancer survivor, Dr. Richard Reiling chose survivorship as the theme of his ACCC Presidency (April 2007–April 2008). What are the key issues in cancer survivorship today from the provider and patient perspective?*

A. From a medical point of view, I think providers need to be prepared to deal with some of the ongoing or long-term effects of cancer. Many people are living longer with cancer, but they are struggling with physical, psychological, or social late effects of the cancer or cancer treatment that can extend many years beyond the end of their treatment. So the focus on survivorship has been for the medical establishment to start paying attention to some of these associated effects.

From the patient's point of view—survivorship is a very unique and individualized experience. There is no one way or one model way of being a cancer survivor. While from the medical point of view we want to provide comprehensive programs and services, from the patients' point of view, they may not always want to take advantage of these services. Simply knowing that these services are available may be helpful.

Q. *What would you suggest are the first components that community cancer centers should attempt to address in their survivorship programs?*

A. The first goal that comes to mind is taking care of any long-term physical symptoms or physical side effects associated with cancer and its treatment. So many of the other aspects of cancer survivorship—psychological well-being, social well-being, quality of life—are so often tied back to physical symptoms. People who have fewer physical symptoms—they don't have pain, they don't have discomfort—are just much better off in many other aspects of their lives.

Then I think the other critical component for a survivorship program is the psychosocial component. Community cancer centers should have trained professionals who can check in and touch base with cancer survivors and assess their functioning in other aspects of their lives.

For example, employment is a critical component.



People take such a financial punch in the stomach as the result of going through cancer treatment today. In fact, 50 percent of bankruptcies in the United States are somehow associated with medical care and people being swallowed up by the cost of medical care. So many other aspects of people's lives are affected by this one issue: the financial impact of cancer.

The focus of a comprehensive cancer survivorship program goes beyond treating the physical late effects. In other words, when a cancer survivor has his or her symptoms addressed but then walks out of the clinic and feels like he or she does not have help dealing with financial issues, it is a missed opportunity. Instead, a social worker or a mental health professional can help identify these long-term problems or issues and then offer assistance.

Q. *What has your research taught you about the needs of cancer survivors?*

A. One size does not fit all. Take support groups, for example. Support groups are valuable for a certain group of people. And I think we still need to do more research into identifying the people who are most likely to benefit from support groups.

The growth of the Internet and the ability of people to go online at 3:00 am and find information or check into a bulletin board, forum, or chat room have opened up a whole new set of support for cancer survivors. People who are more private and not entirely comfortable going to a support group can use these new forms of technology to

access emotional support in the privacy of their own home. So to answer your question, there is no set survivorship “standard.” We have to still try to figure out what’s going to work for which groups of people.

Q. *Can you describe the Impact of Cancer Scale Tool that you’ve developed, which is aimed at assessing the effects of cancer on different aspects of survivors’ lives?*

A. Prior to the development of this scale, there were very few instruments that were measuring the quality of life of cancer survivors. Some of the emerging quality of life scales were attempting to assess areas such as physical, psychological, and social well-being; impacts on spirituality; how cancer affects an individual’s sense of purpose in life, etc. We felt that when you look at these impacts on different people’s lives, it’s hard to tease out how much of those impacts are really related to cancer and how much of those are just naturally occurring changes in life. It was one obstacle we wanted to overcome.

When we look at much of the qualitative research in cancer and listen to and read people’s stories, most cancer survivors talk about how their life has changed after cancer. The other commonality in many stories and narrative is that cancer survivors often talk about how there is an interdependence in the physical, psychological, and social aspects of their lives. In fact, they don’t exist as independent domains. The physical affects the psychological well-being; psychological well-being can affect the extent to which someone feels comfortable interacting out in the social world. If you’re depressed, you don’t want to get up and go to work. And if you don’t have work, it’s going to make you depressed. There’s a two-way arrow that connects these domains. So we wanted to create an instrument that captured that interdependence. The Impact of Cancer Scale Tool has 82 items that cover 10 different domains of people’s lives that seem to be affected by cancer.

Q. *And how can a community cancer program use this tool?*

A. Community cancer centers can give this to cancer survivors and score them in each of the 10 different subscales. There are five positive impacts subscales and five negative impact subscales. So providers can get a picture of the extent to which their patients are saying they have more positive and/or more negative impacts of cancer. One of the interesting results is that it’s not necessarily one or the other. Some people report both high positive changes as well as high negative changes.

Q. *How do you see community-based cancer programs using the information they gathered from this tool?*

A. The information could be used to engage cancer survivors in further discussion about the specific problems they might be having in their life. So for patients who have a really negative perception of the way cancer has affected their life, a social worker or psychologist or mental health professional can then use that information as a starting point to engage a person and say, “Let’s talk about different ways that cancer has affected you.”

For example, one of the subscales is called Life Goals. You could look at someone’s score on this section and get a sense that this person really has no sense of a future; that they really don’t have any sort of guiding light or sense of an overall goal or, if they have goals, they

don’t feel like they can achieve those goals. As a social worker I might then sit down with this person and say let’s talk about this issue: *Why do you feel this way? What do you think are the barriers that are preventing you from either establishing goals for your future or achieving the goals that you have?*

Our scale can help identify and maybe even prevent negative problems that cancer survivor’s might be dealing with, but it also helps to bolster and promote the positives. (The *Impact of Cancer Scale Tool* is available on ACCC’s website at www.accc-cancer.org.)

Q. *Would you describe your current research interests?*

A. My research now is looking primarily at older adolescents and young adults and the impact of cancer in that particular age group. There are data out there to suggest that young people between the ages of 15 and 40 have not experienced some of the improvements in mortality and long-term survival that both pediatric and older adult patients have experienced. Why has this age group not experienced some of the same improvements? There is both theory and data to suggest that it might be the biology of their cancer. It might be the way that physiologically they respond to therapy that’s different from a child and different from an older adult. It might be linked to the time of life. So there is a lot of supposition about what it is about these young adults that their outcomes are disparate.

I have funding right now to do a longitudinal study of young adults, first approaching them within the first few months of treatment and assessing the physical, psychological, and social impacts of their diagnosis and then following them over a period of two years. We hope to be able to tease out useful data from this study because—as I mentioned earlier—one of the struggles is how do you separate the effects that someone is experiencing as related to cancer as compared to what might have happened in their lives normally anyway? By being able to follow young adults longitudinally, we can pay close attention to the changes in their lives that they are attributing to cancer or cancer treatment.

Q. *Can you suggest any good sources of information for community cancer centers and share any final thoughts?*

A. There are some good model survivorship programs, for example, the post-treatment resource center at Memorial Sloan-Kettering Cancer Center. Particularly for young adults, I think a lot of the model programs are Internet based, and I would suggest a website called Planet Cancer as a model for promoting peer support and peer relationships for young adults.

Julia Rowland, PhD, a developmental psychologist who is now director of the Office of Cancer Survivorship at the National Cancer Institute, suggests that in cancer there are universal effects that happen to everybody, and yet, when you then look at it from a developmental perspective, depending on the time in life in which a person is diagnosed, they *experience* those universal impacts differently. A 50 year old diagnosed with colon cancer will have different concerns than a 25 year old diagnosed with Hodgkin’s disease. I would suggest that community cancer centers looking to grow a cancer survivorship program should step back and think about cancer across the lifespan.

Developing a Comprehensive Survivorship Program: Getting Started

by Mary S. McCabe, RN, MA

Since the publication of the Institute of Medicine report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, in 2005, much attention has been focused on the needs of cancer survivors. This consciousness raising has been an essential first step to improving the quality of care for survivors. Still, the most important efforts lie ahead; specifically, there needs to be a national effort to design, implement, and evaluate programs and services that can become part of routine follow-up care.

The Association of Community Cancer Centers (ACCC) has set a wonderful example for all of us who care for cancer patients by taking some of these first steps: first, challenging us to make survivorship a formal component of the continuum of care and second, by publishing a variety of models in *Oncology Issues* to serve as examples of what can be achieved. But let's take a step back from viewing programs that already exist and review how survivorship care is provided today and the essential elements to consider in setting up services and programs for the future.

Getting Started

Today, there are more than 12 million cancer survivors in the United States. We know that post treatment follow-up care is routinely occurring as a matter of practice. However, we also know that the duration of this follow-up care and its associated services varies across the country. Most often follow-up visits, however timed, are focused on surveillance for recurrence, and communication with other healthcare providers about the prior treatment and the plan of care is woefully lacking. What is needed is the development and application of a follow-up plan that is comprehensive yet practical so it can be provided in the community where the majority of cancer care in the United States occurs. Based on the fact that survivors face lifetime health risks that are dependent on the cancer, treatment exposures, genetic predispositions, comorbid health conditions, and lifestyle behaviors, such a plan should include at a minimum:

- Surveillance for recurrence of the primary cancer
- Cancer screening for new cancers using national guidelines
- Identification and management of the physical and psychological effects of cancer and its treatment
- Health promotion recommendations
- Provision of a treatment summary and follow-up care plan (see Figure 1).

Since most busy oncology programs have very limited time and resources for education and counseling, this plan of care need not be provided solely by the oncology team. Rather, a number of models of care can be considered where different providers and organizations take responsibility for various services. For example, the general medical follow-up care components can be “shared” with the primary care provider (a model that is used successfully for other chronic diseases). This type of provider is uniquely suited to manage the health promotion counseling and recommendations for cancer screening. In addition, information about the community organizations offering counseling and other forms of psychosocial support can be provided as part of the package of survivorship care through the development of simple resource lists. This flexible, “shared-care” approach is very important in figuring out how to deliver high-quality survivorship care. What matters most is that there is a plan of care and that, just like with an orchestra, there is a score to be followed, someone in charge, with each independent group working in concert.

What is needed now is action. We must begin to expect good communication between oncologists and primary care providers using the care plan as the communication tool. Acknowledging the expertise of the other providers for important issues such as anxiety, depression, and sexual dysfunction will assure they are addressed by those more expert than the oncology team. As for psychosocial services, remember that you don't have to build it or own it to use it. Most communities have excellent resources for smoking cessation, physical rehabilitation, nutrition counseling, and support groups. Aggressively refer to these organizations and/or partner with them to have survivor-focused programs.

We have a growing body of information about the medical, psychosocial and economic issues facing survivors; we have recommendations from national groups about the importance of addressing this period of oncology care; and we have examples of care models from other disease groups that are effective in providing quality services. So, despite health system barriers and our still evolving knowledge base, it is critically important to get started. Most importantly, our survivors deserve it.

Mary S. McCabe, RN, MA, is director of the Cancer Survivorship Program at Memorial Sloan-Kettering Cancer Center, New York, N.Y.

Figure I. Memorial Sloan-Kettering Cancer Center Summary of Cancer Treatment and Follow-up Plan

Date of Preparation: _____

Name: _____

Cancer Diagnosis: _____

Date of Diagnosis: _____

Date Completed Therapy: _____

Relapse: _____

Cancer Treatment

Surgery

Surgeon/Phone: _____

Date

Procedure

Pathology

Radiation Therapy

Radiation Oncologist/phone: _____

Dates

Type

Field

Dose (cGy)

Chemotherapy/Biotherapy

Medical Oncologist/Phone: _____

Regimen #1:

Regimen #2:

Drug Name

Significant Cumulative Doses
(units or mg/m²)

Follow-up Plan

Visit Schedule

Testing

Screening Recommendations:

Colonoscopy

Prostate specific antigen (PSA)

Mammogram

Other

Nurse Practitioner: _____

An Update on Survivorship Education for Quality Cancer Care

by Marcia Grant, DNSc, FAAN, and Denice Economou, MN, CNS

Survivorship Education for Quality Cancer Care is an education program developed by the City of Hope and funded by the National Cancer Institute. The NCI grant supports four annual courses for competitively selected, two-person multidisciplinary teams from cancer centers across the country. The City of Hope Quality of Life Model for Cancer Survivors provided the framework for curriculum development of the program.

In July 2007, *Survivorship Education for Quality Cancer Care* completed the second of four annual courses. The program was developed to help jump-start survivorship programs across the country by presenting a three-day, goal-driven curriculum, and then following participants' progress at 6, 12, and 18 months post course. (For a description of the first course, held in 2006, see *Oncology Issues*, July/August 2007.)

Applications to participate are submitted by two-person teams from cancer institutions in which one person must be a physician, nurse, or an administrator. The team attends the three-day course together, and is charged with carrying out team goals when returning to their institution. Participants from the first two courses represent 35 states and 102 teams and come from a variety of cancer settings.

Presented by experts in cancer survivorship from across the country, course curriculum is organized around the City of Hope Quality of Life Model of physical, psychological, social, and spiritual well-being. Content relative to cancer survivors focuses on medical care follow-up, surveillance and screening schedules, and supportive care needs. Models of excellence provide examples of active programs from large and small settings. Resources from the course are provided to the participants and include: cancer content, overview of current research, references, and resources in each section of the curriculum.

Course staff is available for support via telephone or email and provide a tri-annual newsletter to update teams on current information and share team successes. Telephone follow-up of participants' goal achievements takes place at 6, 12, and 18 months and provides an opportunity to discuss specific achievements in detail.

Results for the 2006 course at 12 months show a variety of new survivorship activities across the country—ranging from reconfiguring existing support services to building new survivorship programs. For example, some teams have reorganized their psychosocial services under a different name that encompasses survivorship issues including support groups and healthy lifestyle classes; e.g., nutritional changes for weight control

and physical and occupational therapy programs.

Programs are defining survivorship to meet the needs of individual institutions or the resources available. One team is strictly focusing on the transition period from treatment completion to two years post treatment. Their focus then becomes more on long-term side effect management and psychosocial issues related to distress and anxiety associated with ending treatment. Other teams are organized around diseases and focus their activities on disease-specific surveillance recommendations and providing specific care planning for patients and primary care physicians. Specific models of care vary according to the settings and staff as well.

Multidisciplinary teams providing survivorship follow-up clinics are primarily seen in large academic medical settings. Community cancer centers provide care appropriate to their settings, using local resources such as church groups or community groups, as well as larger psychosocial support groups like CancerCare or the Wellness Community, American Cancer Society, and Lance Armstrong Foundation. This collaboration helps provide additional support to meet patients' and families' needs. *Survivorship Education for Quality Cancer Care* has begun to help teams put into practice the recommendations of the IOM report and develop the range of activities and models that can combine settings' resources—both structural and professional—to meet those needs.

The second *Survivorship Education for Quality Cancer Care* course has just completed the 6-month follow-up and goal achievements are positive. Institutional surveys comparing 2006 and preliminary 2007 participants at baseline and 6 months show a change in baseline data on how supportive administration is to survivorship care. The results for how receptive, how comfortable, and how effective survivorship care is within the institutions compare closely at baseline. The comparison of barriers identified in 2006 and 2007 courses at baseline found similar results. The top two barriers to survivorship care remain: 1) lack of survivorship knowledge, and 2) financial constraints.

The coordination of resources and the goal-driven education provided by the *Survivorship Education for Quality Cancer Care* effort has provided significant momentum to help participating institutions jump-start changes. The third course is scheduled for July 16 – 19, 2008. Applications are closed for the 2008 program; however, a fourth and final course will be offered in 2009. For more information go to <http://www.cityofhope.org/CME/Survivorship/SurvivorshipHome.htm>.

Marcia Grant, DNSc, FAAN, is director and research scientist, Department of Nursing and Research Education, and Denice Economou, MN, CNS, is project director, Survivorship Education for Quality Cancer Care, at City of Hope in Duarte, Calif.

Living in the Future Cancer Survivorship Program

Survivorship as a distinct phase of care in the community setting

by Carol A. Rosenberg, MD, FACP

The *Living in the Future* (LIFE) Program at Evanston Northwestern Healthcare (ENH) provides continued care for post-treatment cancer survivors, facilitating a smoother transition from the oncology specialty care environment back to the community, the family, and the primary care setting. The LIFE Program earned a community grant from the Lance Armstrong Foundation in 2006. Now in its second year of operation, the program has been recognized by survivorship experts for its commitment to the long-term care of cancer survivors and serves as a national model of an effective survivorship program in a community setting.

As founder and director of the LIFE program, I am proud of our program's groundbreaking accomplishments and believe our experience will benefit others in improving survivorship care nationwide. I also maintain the role of physician champion is critical to creating institutional commitment to comprehensive survivorship services. Essential to any champion's efforts are the merging of science and passion. In my experience, the unique responsiveness of the community care environment makes it the ideal setting to nurture and grow these critical services.

The Institute of Medicine's (IOM's) 2005 report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, brought public attention to the healthcare service gap experienced by cancer treatment survivors exiting their treatment regimen and re-entering their lives.¹ Post-treatment continuity with primary care providers and other community support services were either non-existent or difficult to navigate, especially when seeking services close to home.

For ENH, obstacles to providing comprehensive survivorship care included:

- A lack of community funding designated solely for survivorship programming
- An absence of clarity about roles and responsibilities for management of care of long-term cancer survivors
- A lack of awareness about survivorship issues among the general public as well as healthcare providers
- An emphasis on curative results at the expense of long-term physical and quality-of-life outcomes
- Knowledge deficits and random collaboration on the part of healthcare professionals.

All of these factors contributed to a lack of programs and services that focused on cancer survivors as they exit the high-technology treatment model to return to their primary care healthcare model, families, and communities. In designing the LIFE program, my vision was to create

a program that would fill these gaps and serve as a bridge between initial treatment and post-treatment care.

The LIFE Program

The LIFE program is the first community program in our region specifically designed with the recommended cancer survivorship guidelines from the Institute of Medicine. The LIFE program is molded to meet the specific needs of the community it serves while its protocols stay in step with leading research. The goal of LIFE is to create a straight path from post treatment back to the community, family, and primary care setting.

The LIFE program establishes cancer survivorship as a distinct phase of care within the ENH cancer care continuum—a new model for the healthcare industry. ENH's primary service area includes northeast Chicago, and north and northwestern suburbs, with a population of 1.5 million. In 2006, the ENH Cancer Registry recorded 2,810 new cancer cases: 93 percent of these were diagnosed at ENH. Of that number, 97 percent of patients chose to receive treatment at ENH, an NCI-designated Community Clinical Oncology Program (CCOP). We know directly from surveying ENH patients treated at any one of the three Kellogg Cancer Care Centers, that once their treatment regimen is completed, patients are uncertain where their "new" medical home should be, how to return to an informed primary care practitioner, how to monitor their health, and where to go to marshal other resources.

Within this community hospital context, I envisioned the LIFE Cancer Survivorship Program as a multifaceted program to promote individualized healthcare and self management at the re-entry phase following oncology treatment.

The LIFE survivorship care model provides transition strategies aimed at cancer patients who are at least three months out from an active treatment regimen and are referred by an ENH medical, surgical, or radiation oncologist. A key factor in creating the LIFE care model is that patients first diagnosed and treated at ENH remain within the ENH family of healthcare providers for post-treatment activities. The majority of people treated at ENH, live in its service area and seek care close to home. Nearby survivorship services and programs not only mean easy physical access for patients but also that cancer care providers remain in the care continuum if and when needed.

LIFE Survivorship Care Plan

Patients first connect with the LIFE Program through a patient-centered, risk-adapted consultation visit with Carole Martz, RN, AOCN, the program's clinical coordinator, an advanced practice oncology nurse with expertise in cancer survivorship. The LIFE program is designed to become the survivor's guide. The timing of the risk-adapted risk is crucial, allowing survivors to take advantage of a "teachable moment" when they may be anxious



“Care by the community, for the community” is how Carol A. Rosenberg, MD, (top photo, center) describes the ENH LIFE Cancer Survivorship Program. The LIFE Program helps educate and empower cancer survivors, assisting them in the transition from the oncology specialty care environment back to the community, the family, and the primary care setting. Pictured below (L to R) are oncologist Leon Dragon, MD, director of the ENH Highland Park Kellogg Cancer Center; breast cancer survivor Helen Hackett; Carol A. Rosenberg, MD, director of the LIFE Program; and Carole Martz, RN, AOCN, clinical coordinator of LIFE.

about their next healthcare steps and eager to be educated and proactive about ensuring their future health.

The goal of the risk-adapted visit—which is provided free of charge—is to provide a framework for the design of a personalized survivorship plan. This face-to-face, one-hour visit is tailored to each survivor as a unique individual, and includes:

- Customized education about future risks
- Medical surveillance guidelines
- Directed navigation to health professional services
- Survivorship resources.

The visit also serves as a communication vehicle between the survivor and his or her healthcare providers. It is the basis for a dialogue about what has happened, what the future may hold, the resources available for addressing current and anticipated problems, and the roles of all involved (both survivor and healthcare providers) going forward.

Survivorship Care Plan tools include a customized Survivorship Care Plan (for example, see the breast cancer Survivorship Care Plan template on pages S14–S15). At our program, these templates are in an electronic format. The Survivorship Care Plan becomes part of the patient’s medical record, and the patient also receives a consolidated hardcopy, printed out at the time of the risk-adapted visit as a portable detail for his or her own records. ENH was among the first multi-site healthcare systems to become completely electronic and is a paperless institution. All patients have an electronic health record (EHR) that can be accessed through a password protected website. The LIFE Survivorship Care Plan works well in the ENH ecosystem by recycling medical information available in our EPIC computer system, and applying it into useful formats such as the Survivorship Care Plan. This technology has revolutionized survivorship care for the community by making the sharing of information between survivors and their healthcare providers more efficient. In fact, the electronic format of the LIFE Survivorship Care Plan has actually surpassed the progress of larger medical centers.

For each survivor, LIFE’s clinical coordinator and I develop a customized Survivorship Care Plan that includes:

- An understandable summary of the patient’s diagnosis and treatment history;
- Guidelines for continued monitoring of recurrence and second malignancy;
- Long-term consequences of cancer treatment;
- Recommended lifestyle modifications;
- Assistance in selecting a primary care physician who follows recommended IOM’s survivorship guidelines; and
- Navigation to LIFE’s community-based programs, which address all aspects of survivorship including lifestyle, employment, insurance, fertility, psychosocial services, and legal protection.

Survivorship Education for the Community

Once an individual’s Survivorship Care Plan is in place, the LIFE program helps to further educate survivors on how to be effective self advocates and offers a variety of free health education options. The LIFE website (www.enh.org/life) offers survivors access to an online array of survivor resources and links, including daily updates in cancer news from the American Cancer Society, and a calendar of upcoming LIFE events and programs. The website provides online registration for LIFE seminars and interactive

continued on page S16

Sample Template: Breast Cancer Survivorship Care Plan

Risk-Adapted Visit—LIFE Program

Page 1

Patient Name:	Medical Record Number:
Birth Date:	Date of Encounter:
Age at Diagnosis:	Hormonal Status at time of Diagnosis:
Family History of Cancer:	
Date of tissue diagnosis:	Pathological Findings:
Stage: TNM	

Initial Treatment Plan

(Treatments received, dates, locations, and providers)

Surgery

	Right	Left	Bilateral
Lumpectomy			
Mastectomy			
Sentinel node biopsy			
Axillary lymph node dissection			
Reconstruction			
Radiation Therapy			
Whole breast			
Partial breast			
Boost			
Total dose			
Reconstruction			

Chemotherapy (with dose details)

Hormonal Therapy (with dose details)

Unusual or Noteworthy Toxicities During Treatment

This section is comprised of 30-40 drop down boxes. If selected the drop down box offers smart text. Examples: an allergic reaction to some form of therapy; treatment delays due to neutropenia; passage of kidney stone during chemotherapy; etc.

Expected Short- and Long-term Effects of Treatment

This section is comprised of 30-40 drop down boxes. If selected the drop down box offers smart text. Examples: alopecia; amenorrhea; fatigue; hot flashes; memory changes; etc.

Potential Late Effects of Treatment

This section is comprised of 30-40 drop down boxes. If selected the drop down box offers smart text. Examples: premature menopause, infertility; fatigue; weight gain; etc.

Late Toxicity Monitoring Needed

This section is comprised of 30-40 drop down boxes. If selected the drop down box offers smart text. Examples: thyroid testing; bone density; mammography; lymphedema assessment, etc.

Narrative section includes recommendations for how often these tests should be performed, the medical reason why, and who should order them.

Sample Template: Breast Cancer Survivorship Care Plan
Risk-Adapted Visit—LIFE Program
Page 2

Surveillance for Potential Recurrence of Primary Cancer (narrative)

Included here are recommendations as to how often breast examinations, diagnostic mammography, or other surveillances for the primary cancer should be performed and by whom.

Surveillance Needed to Monitor for Second Primary Malignancies (narrative)

Narrative that alerts to the development of second malignancies and suggests surveillance testing, how often, and with which provider based on the patient's cancer, treatment, and other personal risks. For example, BRCA testing in a young woman with breast cancer; gynecologic assessment for a woman on tamoxifen as surveillance for endometrial cancer; etc.

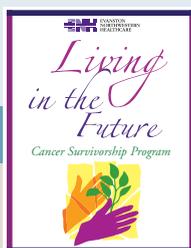
Physicians Identified for Monitoring Toxicity, Recurrence, and Second Malignancies

Included here are drop down boxes with names and contact information, e.g., primary care provider; gynecologist; surgeon, etc., with narrative which suggests those providers most appropriate for monitoring for toxicity, recurrence, and second malignancy.

Identified Psychosocial and Health Concerns

Included here are drop down boxes (with smart text). Drop down box examples: concerns about cancer recurrence; late effects of treatment; vaginal dryness; weight gain; fatigue; depression; osteoporosis; cardiac disease; smoking cessation; nutrition; diet; sleep problems; sexuality; insurance; employment; etc.

These are combined into a narrative format that includes both physician *and* survivor concerns. The survivor's "pre-visit" self assessment and/or concerns are discussed and documented here.



Prescription for LIFE (narrative)

This section is the heart of the Survivorship Care Plan. It provides key information that is used both by the survivor and the survivor's healthcare providers going forward.

Herein is an extensive, understandable narrative that summarizes and integrates all of the above information. This section also provides navigation for the survivor through a wide array of accessible LIFE program offerings, such as the LIFE *Survivorship 101* series seminars and *Evenings of Survivorship Symposia* and other specific survivorship community resources to optimize physical and emotional health.

The plan also delineates modifiable health behaviors along with ways and programs to address them. For example: smoking cessation; dietary changes; decreased alcohol consumption; increased physical activity.

workshops designed to address common concerns of cancer survivors, including the LIFE Survivorship 101 Seminar series: *Thriviship* and *LIFE's Evenings of Survivorship*.

Held in collaboration with the American Cancer Society, the LIFE *Survivorship 101* seminars are two-hour group workshops offered monthly to all in the community. These workshops cover major topics related to cancer survivorship, as well as promote the acquisition of skills to understand, select, and navigate community-based cancer survivor resources.

Seminar topics include: *Eat to Beat Malignancy and Walk Away from Cancer*, *Self Esteem and Sexual Intimacy*, and *How LIFE Events Impact Insurance and Employment*. Facilitating the workshops are experts in the science of survivorship, including the LIFE program's physician director and nurse clinical coordinator, dietitians, psychologists, social workers, and lawyers. Seminar participants receive comprehensive written materials that explore and reinforce the information presented.

LIFE also partners with the Wellness Community to present larger regional symposia—*Evenings of Survivorship*. These multiple interactive workshops focus on topics such as: *Tired of Not Sleeping*, *The New Normal*, *Coping with Cognitive Changes*, *Stress Reduction Techniques*, and *Food Facts and Myths for Survivors*.

Survivorship Education for Healthcare Professionals

Although healthcare providers can play a pivotal role in improving the long-term health of cancer survivors,² few healthcare providers have received training on follow-up care for survivors post treatment.^{3,4} To facilitate the critical competencies that should be part of the routine care for cancer survivors, the LIFE Health Professional Education Course and accompanying manual, are offered to all community healthcare professionals in centralized locations and lecture settings including Grand Rounds, academic conferences, and keynoted engagements for regional organizations such as the Wellness Community.

As director of the LIFE Program, I develop and present the program's health professional course and manual resource, which include the topics: prevention of secondary cancers, late effects and long-term complications of cancer and its treatments, quality-of-life issues, and lifestyle imperatives for cancer survivors. Healthcare professionals attending these courses receive CME and CEU credit, and also become "primary care partners" with LIFE—membership on an ever-increasing LIFE resource roster of community healthcare providers who are knowledgeable in the after care of cancer survivors.

Care by the Community, for the Community

Since the LIFE program began in November 2006, we have conducted more than 350 risk-adapted visits with survivorship care plans and reached another 500 survi-

vors through the *Survivorship 101 Seminars and Symposia*. Additionally, LIFE has helped more than 700 healthcare professionals gain critical professional understanding of survivorship issues through continuing medical education courses targeted to this specific audience.

While many large academic medical institutions across the country are developing survivorship programs, ENH is unique in that it has developed and implemented a successful *community* prototype.

The LIFE program is funded in part by ENH as well as through a two-year community education implementation grant from the Lance Armstrong Foundation. Two years of external funding have been granted from the community's Healthcare Foundation of Highland Park, the Myra Rubinstein Weis Health Resource Center, Kemper Educational and Charitable Foundation, and various individual charitable contributions. This combined support has covered personnel expenses for the program director and the nurse clinical coordinator, as well as a stipend for non-personnel expenses, such as course materials, specified survivorship space, and training and seminar speakers.

The Lance Armstrong Foundation's theme of "knowledge is power" is what drives LIFE's educational goals. By providing each cancer patient who exits treatment with a Survivorship Care Plan and specialized educational seminars and resources, and by offering healthcare professional competency courses, LIFE creatively, collaboratively, and compassionately plays a proactive role in addressing the survivorship needs of the community it serves. LIFE is paving the way for other community cancer centers to follow its example as more and more cancer survivors look forward to ...Living in the Future.

Carol A. Rosenberg, MD, FACP, is founder and director of the Living in the Future (LIFE) Cancer Survivorship Program and director, Preventive Health Initiatives at Evanston Northwestern Healthcare in Illinois.

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Improving Survivorship Care: A Community Cancer Center's Approach

by Marlene A. Runyon, RN, BSN, OCN®, CHTP; Diane M. Otte, RN, MS, OCN®, and James E. Novotny, MD, FACP

In the spring of 2006, Franciscan Skemp Healthcare (FSH), a 160-bed hospital located in La Crosse, Wisconsin, took a bold step forward in addressing the needs of cancer survivors and their families. The Cancer Center applied and was accepted as one of 48 teams competitively selected from cancer programs across the United States to participate in the July 2006 *Survivorship Education for Quality Cancer Care* conference, a National Cancer Institute (NCI)-supported program at the City of Hope (COH) in Duarte, California. The conference brought together national experts and teams representing healthcare professionals from across the United States to learn how to improve cancer survivorship care in their home communities. (For more information, see page S11.) Attending the conference from FSH was a BSN-prepared nurse with oncology nursing certification who serves in a unique role as Cancer Guide at our program, and a Cancer Center social worker.

Conference Highlights

The conference theme centered on institutional change and the development and implementation of new programs—with the goal of improving quality of care and quality of life for cancer survivors. Attendees received updates on the current status of cancer survivorship in the United

States. National experts in the field of cancer survivorship provided “State of the Science” seminars, describing how survivorship affects four dimensions of quality of life: physical, psychological, social, and spiritual. Innovative community programs supporting quality of life for the cancer survivor were featured in “Models of Excellence” seminars.

Where to Begin?

Participants were encouraged to develop institutional goals with COH providing follow-up and support for 18 months post conference. The FSH team developed the following three goals:

1. By January 1, 2007, 90 percent of FSH/Mayo Cancer Center staff and providers will participate in survivorship education offered through two, one-hour workshops and demonstrate understanding measured by a pre- and post-test.
2. By June 1, 2007, 50 percent of radiation and medical oncology patients who have completed treatment will receive a survivorship care plan that will also be sent to the primary care provider.
3. By June 1, 2007, 75 percent of radiation and medical oncology patients who have completed treatment will



The multidisciplinary Survivorship Planning Team at Franciscan Skemp Healthcare included representatives from all areas of the Cancer Center.

PHOTOGRAPHS COURTESY OF THE CANCER CENTER AT FSH.

receive a “Life after Treatment” packet of survivorship resources to support them in their transition.

With the excitement generated by the survivorship conference and the full support of FSH administration, the Cancer Center then began to create the area’s first cancer survivorship program. The staff who attended the COH conference became the project coordinators. Our first goal was to provide survivorship education for Cancer Center staff and providers through two in-service training sessions. Using resources and information from the COH conference, we developed educational sessions focused on recommendations from the Institute of Medicine (IOM) report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, including the excellent video by the same title.¹ The specific training objectives for both in-service sessions are outlined in Table 1.

The Planning Process

More than 90 percent of the Cancer Center staff attended the in-service trainings. With enthusiasm high, finding volunteers to serve on the Cancer Survivorship Planning Team was not a problem. The 18-member team, which included representatives from all areas of the Cancer Center, held its first meeting in November 2006. FSH primary care providers also participated in the Planning Team serving in a consultative capacity throughout the planning process. (Table 2 is a complete listing of Cancer Center staff; an asterisk denotes participation on the Survivorship Planning Team.)

The Survivorship Planning Team received exceptional support and guidance from the Cancer Center director and providers. Throughout the planning process their energy and commitment to the project helped propel the team forward. Team brainstorming sessions focused on nine core areas of survivorship planning that, due to finite staff and resources, were refined to focus on the following six areas:

1. Cancer survivorship care plan and exit interview process
2. Institutional, provider, and community awareness and communication
3. Pilot project policy, procedures, and outcomes
4. Psychosocial and spiritual care, including patient and family follow-up support (hospice, spirituality, bereavement, loss, and grief)
5. Wellness programming
6. Survivorship resources for patients and families.

Facilitated by a group leader, work groups met independently on a weekly or bi-weekly basis for six months, and reported back to the larger planning group each month.

Publicity and Marketing Strategy

The planning team worked with the FSH marketing director to develop a communication plan to announce our survivorship program, which would be the area’s first. We

developed an internal and external communication plan that included a situation analysis, program components, communications objectives, audiences, spokespersons, and the target date for launch to area media.

The planning team brainstormed names for the new program. The chosen name was then taken to focus groups and also went through our internal approval process. On March 7, 2007, via news releases, TV, and radio interviews as well as an internal bulletin, the Cancer Center announced the formation of *Living Well: A Program for Those Surviving Cancer*, with a pilot project to begin June 1, 2007.

Program Overview

The goal of the *Living Well* program is to improve quality of care and quality of life for cancer survivors and their families and caregivers; and to provide for continuity of care between oncologists, specialists, and primary care providers ensuring that all of the survivors’ health needs are met. Over a six-month period, from November 2006 to May 2007, the Survivorship Planning Team finalized program policies and procedures (see Table 3).

The *Living Well* program has two components. Part One consists of an array of supportive services, resources, and educational events offered to all patients and families during the course of their treatment and beyond. Part Two is a six-month pilot program. For this pilot project—following the suggestion from COH conference leaders—the team choose to start small. With input from oncology providers, we decided to unroll the pilot survivorship project for patients with lymphoma, head and neck, and colorectal cancer. Our rationale was that this population would include high-risk patients of both genders and various ages.

The pilot program addresses end-of-treatment survivorship needs, including a comprehensive cancer survivorship care plan for the patients and their primary care providers and other specialists, and follow-up interviews within six weeks of the end of treatment to provide support for survivorship needs and set new goals for healthy living.

Cancer Survivorship Care Plan and Patient Exit Interview

We developed a survivorship care plan template by using the Cancer Survivorship Care Plan from the IOM Fact Sheet (Cancer Survivorship Care Planning, November 2005)² and by looking at various survivorship care plans. The template provides a summary of treatment and addresses the risk of recurrence, surveillance, prevention, coordination of care between providers, and improving quality of life. Table 4 outlines the components of the survivorship care plan.

Much discussion centered on how to make the plan electronically available to all FSH providers, as FSH does

continued on page S20

The reception desk at the Cancer Center at Franciscan Skemp Healthcare in LaCrosse, Wisconsin.



Table 1. Survivorship In-service Training Objectives

November 2006 In-service: *“Introduction to Cancer Survivorship”*

1. Describe the current status of adult cancer survivorship in the United States.
2. Recognize the impact of cancer survivorship on quality of life.
3. Share conference goals for FSH Cancer Center for survivorship program.

December 2006 In-service: *“Developing a Comprehensive Cancer Survivorship Program”*

1. View *From Cancer Patient to Cancer Survivor: Lost in Transition*.
2. Describe essential components of survivorship care.
3. Discuss barriers facing cancer survivors.
4. Look at existing model programs.
5. Brainstorm ideas for FSH survivorship program.

Table 2. FSH Cancer Center Staff *

- 1 director*
- 3 medical oncologists*
- 1 radiation oncologist
- 1 radiation physician assistant*
- 1 oncology certified clinical nurse specialist*
- 1 pharmacist
- 1 pharmacy technician
- 1 phlebotomist
- 9 oncology certified nurses*
- 1 research nurse
- 1 cancer registrar
- 1 cancer registry assistant
- 1 Cancer Guide nurse*
- 1 dietitian*
- 1 chaplain*
- 1 social worker*
- 1 radiation supervisor*
- 1 radiation dosimetrist
- 1 radiation physicist
- 5 radiation therapists*
- 1 radiation medical secretary
- 6 patient service representatives (receptionist/scheduler/patient roomer) *
- 3 Reiki volunteers
- 1 massage therapist
- 10 volunteers*

*Denotes representation on the Cancer Survivorship Planning Team.

Table 3. Living Well Policies and Procedures

- ✓ Patients with head and neck, lymphoma, or colorectal cancer will receive a Survivorship Care Plan at the end of their treatment summarizing critical information needed for the survivor’s long-term care.
- ✓ The Cancer Center interdisciplinary team will review the plan and update as needed.
- ✓ A hard copy of the Survivorship Care Plan will be sent to the primary care provider, and be available on the electronic portal.
- ✓ Cancer Center oncologists will be responsible for follow-up cancer surveillance, including tests and scans.
- ✓ Primary care providers will be responsible for follow-up cancer prevention, healthy living goals, and primary care needs.
- ✓ Select patient populations will be directed to their primary care provider for cancer surveillance or to an identified other provider, i.e., ENT, Urology, etc.
- ✓ The Cancer Center will contact the patient’s primary care provider at the end of treatment to notify them that the patient has ended his or her course of treatment and schedule an appointment.
- ✓ In the event the patient does not have a primary care provider, or wishes to change providers, the Patient Service Representative will assist the patient to follow up with the primary care provider of his or her choice.
- ✓ At the completion of treatment, or within six weeks of completing treatment, the patient will meet with the Cancer Guide for an exit interview.

Table 4. Survivorship Care Plan Components

- List of providers
- Diagnosis (type of cancer, grade, stage)
- Treatment history (type of treatment, drugs, dosages, possible adverse effects and responses)
- Potential long-term effects from therapy
- Recommended cancer surveillance
- Signs and symptoms of cancer recurrence
- Psychosocial and spiritual concerns
- Healthy living goals
- Cancer team recommendations and patient goals
- Resources (availability of psychosocial services in the community).

not currently have an electronic medical record (EMR). With the help of FSH information technology specialists, a care plan template was incorporated into the existing Clinician Portal, an electronic patient information repository.

The patient receives the care plan within six weeks of completing treatment at an exit interview with the Cancer Guide. The purpose of the exit interview is to:

- Go over the care plan and follow-up recommendations
- Review patient needs and establish mutually-agreed-upon goals for healthy living
- Make referrals as needed, i.e., behavioral health, integrative therapies, support groups, community services
- Provide the Survivorship Resource Packet
- Ensure the patient has an appointment established with primary care provider
- Encourage participation in ongoing program offerings.

Pilot Patient and Physician Surveys

Pre-pilot surveys were developed to serve as a baseline to evaluate the pilot project. The surveys were sent to patients who had completed cancer treatment in the three-month period prior to the start of the pilot project. Primary care providers for these patients received a physician survey.

An 11-question survey was sent to 37 patients with a 46 percent response rate. Results indicated a need for better communication about the risk of cancer recurrence (70.5 percent felt informed or very informed), the potential late effects of treatment (82.3 percent felt informed or very informed), and setting goals for healthy living (82.4 percent felt supported).

Twenty-seven provider surveys (12 questions) were sent, with a 37 percent response rate. These results indicated the need for better communication about the risk of cancer recurrence (10 percent felt informed) and potential late effects of treatment (30 percent felt informed).

The *Living Well* pilot project ran from June 1 to December 31, 2007. Sixty-eight patients were enrolled in the project. Twenty-nine patients have completed their treatment, and 15 exit interviews have been completed to date. Verbal feedback has been positive from both patients and providers. Project coordinators are currently gathering data and mailing post-pilot surveys. Final program evaluation will be completed when all pilot patients have completed their cancer treatment, received their care plan, and participated in the exit interview.

From the beginning, the Survivorship Planning Team followed the FSH institutional approval process, involving administrative officials, the Cancer Center Clinical Practice Committee, and the FSH Cancer Committee. When the pilot project evaluation is complete, the results will be shared with the FSH Clinical Practice Committee.

Moving Forward

The Survivorship Planning Team faced challenges along the way. Staff time and energy are limited, and the project

coordinators have other full-time responsibilities. As we move forward with the program, we will need to:

- ✓ Identify who will keep the Survivorship Care Plan up to date.
- ✓ Decide which cancer diagnoses will be included in the survivorship program and when.
- ✓ Integrate the Survivorship Care Plan into the EMR without having to re-create the wheel. FSH is currently moving toward an entirely electronic system.
- ✓ Know the staffing requirements required to effectively coordinate the program.
- ✓ Ensure that staff has adequate time and resources to address all the pressing needs of the survivorship program.
- ✓ Identify reimbursable services.

Despite these challenges, the Survivorship Planning Team is committed to the success and continuation of the *Living Well Survivorship Program*. With the help of volunteers, cancer survivors, and existing staff, our goal is to expand services to include the following six areas:

1. Sexuality and intimacy
2. Genetic counseling
3. Rehabilitation and pain and symptom management
4. Community awareness and education
5. Caregiver and family support
6. Survivor and family retreats.

The support of the entire institution, administrators, providers, nurses, and other Cancer Center staff has been key to the success of the project. The survivorship training, resources, and online and phone support provided by City of Hope Survivorship Education staff has been crucial. However, the wholehearted, hands-on support from the Cancer Center director, our oncology providers, and the entire Cancer Center staff has truly brought about the success of the *Living Well Cancer Survivorship Program*, improving survivorship care and quality of life for our patients and families.

Marlene A. Runyon, RN, BSN, OCN®, CHTP, is the cancer guide; Diane M. Otte, RN, MS, OCN®, is the director; and James E. Novotny, MD, FACP, is medical oncologist and medical director of the Cancer Center of Franciscan Skemp Healthcare in La Crosse, Wisconsin.

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A Model Cancer Wellness Program

Exercise and art in cancer survivorship

by Amy Litterini, PT, DPT

I had a vision in my mind of the defined components of a comprehensive cancer center. If you choose to engage in cancer care, you certainly need state-of-the-art treatment modalities for medical oncology and radiation oncology, and a formal research program; but I wanted something more. I wanted to actively engage our patients and their families at perhaps the most difficult time in their lives and help them with their individual journey. What we accomplished—with this framework and this vision—was the Cancer Wellness Program.

Mary Palmer, RN, MBA
Vice President of Cancer Care Services
at Exeter Hospital

Exeter Hospital is a 100-bed facility on the seacoast of New Hampshire recognized by the American College of Surgeons Commission on Cancer as a Comprehensive Community Cancer Center. Since 1980, medical oncology care has been provided at the Center for Cancer Care at Exeter Hospital by New Hampshire Oncology Hematology, PA, and in 2004, services expanded to include radiation oncology. In 2002, the Center for Cancer Care added the Cancer Wellness program to provide a wide variety of comprehensive support programs that offer individual and group services to help patients manage cancer and treatment-related side effects.

The Wellness Program's core services are traditional counseling, nutrition, and rehabilitative care, which include the Cancer Well-fit™ exercise program and such integrative oncology services as yoga, massage, and Reiki. Support groups are offered for individuals, couples, gender-specific survivor groups, and for those with metastatic disease. Supportive programs in the creative arts include art therapy, journaling, and individual and group art instruction. Other specialized programming includes pet visitation, *Look Good...Feel Better*, a weight management program, and an outdoor ropes course offered in collaboration with the University of New Hampshire.

The Art of Wellness

Exeter Hospital's slogan, *The Art of Wellness*, is a perfect fit for the Wellness Program at the Center for Cancer Care where a resident artist and an art therapist, both master's prepared, provide an array of creative support programs for patients and their loved ones throughout their cancer journey.

Lori Nathan, ATR, the cancer center's art therapist since 2002, offers group art therapy for adult survivors, a family art program for the children and grandchildren of patients, and a writing program.

Kathleen Robbins, MFA, joined the Cancer Center's Wellness Program as resident artist in 2006. She provides a weekly healing arts class, taught in

Resident artist Kathleen Robbins (on right) offers one-on-one art instruction to a patient in the cancer center's infusion area.



a traditional classroom setting, as well as one-on-one art instruction in the infusion area from the rolling art cart she created. Patients start with a demonstration on the basics with all the materials provided, and then the patient is set up to paint with a mentor. Over the past few months, the one-on-one art sessions have expanded as more survivors have expressed interest in learning basic watercolor technique. Patients have been painting apples, flowers, and landscapes from photographs while receiving their infusions in the medical oncology clinic. In addition to the traditional arts, patients have also enjoyed making cards and scrapbooking.

Robbins also teaches a traditional art class that meets weekly in the cancer center's conference room and involves a group of survivors. The class explores a variety of techniques and materials from acrylic painting to charcoal drawing and mixed media exercises that include collage and assemblage. Participants work from nature as well as their imagination and enjoy exploring and discussing their unique individual expressions. The class goal is to let the creative process become the springboard for the emotional, spiritual, and creative growth of the individual while also encompassing a support group activity.

Hundreds of patients have participated in creative art services since the Cancer Center's art program was initiated in 2000 as a pilot project. In fiscal year 2007 alone, 98 new participants were provided services. Artwork created by the participants has been exhibited in the hospital and at local libraries and galleries. Permanent art displays are on view in both the Cancer Center and the Synergy Health & Fitness Center, which is located on the hospital campus. The Cancer Center's new patient orientation manual, new patient educational DVD, and the program's quarterly *Wellness* newsletter also feature patient artwork. All art programs are free of charge to patients. The cost of staffing and supplies is included in the Cancer Center's annual operational budget. Additional funds for special art projects have been made available by generous donations from local fundraisers.

Cancer Well-fit™

Synergy Health & Fitness Center (Synergy) on Exeter Hospital's campus has hosted the Center for Cancer Care's Cancer Well-fit™ exercise program since its inception in 2002. Synergy, a 40,000-square-foot, hospital-based community health club built in 1998 with an average of 4,000 members, is also home to outpatient physical therapy services for oncology care and lymphedema management.

Cancer Well-fit™ is a free, twice-weekly program lasting 20-weeks, or for the duration of cancer treatment, whichever is longer. The program is designed to help manage the physical and emotional side effects of cancer treatment for survivors within one year of diagnosis. To date, the Well-fit™ program has served more



The Well-Fit™ staff (top row from left) Tammy Mazur, BS; Patti Bartlett (seated center); Amy Litterini, PT, DPT; Christine Bucu, BS and Chuck Memmesheimer, PTA, (bottom, left).

than 1,000 cancer survivors from the community.

The Cancer Well-fit™ program is staffed by a physical therapist, who is employed by the Cancer Center, and eight oncology-trained personal trainers (employed by Synergy). These personal trainers supervise 10 individual classes per week for 50-75 patients per day twice weekly. In addition to traditional exercise, the Cancer Center also offers yoga with the goals of relaxation and improved posture, breathing technique, and flexibility. Two yoga classes, taught by oncology-trained yoga instructors, are provided each week.

Cancer Well-fit™ participants receive an individualized exercise program consisting of cardiovascular, strength training and flexibility exercises, offering a comprehensive approach to fitness. Participants are assessed by a doctoral-prepared oncology physical therapist before starting their exercise program, and a group of oncology-trained personal trainers assist them with proper set up, technique, and progression of their exercise program.

As fatigue is one of the most common complaints in cancer survivorship, the Cancer Well-fit™ program was initiated to help patients reduce fatigue and maintain strength and endurance while undergoing treatment. Research has routinely demonstrated benefits from exercise on cancer related fatigue, as did the cancer center's own 2007 study of 200 heterogeneous participants.¹ Other statistically significant benefits for study participants overall included increased grip and lower extremity strength, and improved quality of life. The program is planning additional research studies to examine the benefits of exercise in patients with Stage IV cancer.

Training the Trainers

Most rehabilitation and fitness professionals do not learn oncology principles during their core training curriculum; therefore, oncology education is a requirement for individuals interested in initiating a cancer exercise program. In 2001, Exeter Hospital initiated an internal two-day mandatory training curriculum for our rehabilitation and fitness professionals involved in cancer care. The curriculum includes basic and advanced lectures from physicians, nurses, social workers, therapists and other oncol-

Just Getting Started?

Once a community cancer center decides to develop comprehensive survivorship services, the first steps are to establish a framework for goal setting and a timeline, keeping its mission and vision in mind. Community cancer centers should also consider conducting site visits and benchmarking against other longstanding successful programs. Consider the format that best fits your organization and seek similarly sized programs to emulate. For example, before starting our exercise program, three staff members (the director of Cancer Wellness Services, the cancer center director, and the vice president of oncology) traveled to Santa Barbara, Calif., to look at the original Cancer Well-fit™ program at the Santa Barbara Athletic Club. On our return, we spent six months designing our exercise program to enhance our existing oncology rehabilitation program by meeting our clinical and medical setting needs, developing our policies and procedures, and establishing an educational plan.

Community cancer centers should develop individual processes and procedures in order to customize the program to their specific needs—budget, patient population and volume, available space, staffing, and expertise.

ogy professionals in order to provide a solid foundation for our staff. Topics include medical oncology, radiation oncology, pathology, radiology, surgery, and end-of-life care. Special topics have included lymphedema, pain management, yoga, oncology massage, and spirituality. Today, this annual program is attended by an average of 75 professionals from regional facilities throughout New England, and educational offerings have expanded to include hosting site visits and providing onsite training consulting for other facilities.

Program Costs

The Cancer Well-fit™ Program at Exeter Hospital is free to any patients from the community regardless of where they receive their treatment. Patients outside of our system are referred to us by their friends, family, and/or their physicians. All patients are required to have medical clearance prior to initiating the program. Originally, the program was funded, as a pilot project, by a \$25,000 grant from the Exeter Hospital Associates. Today the expenses for the program are included in the operational budget of the Cancer Center. The annual contract with Synergy includes monthly payments for space rental, equipment usage, and an hourly group fitness rate for the personal training staff. This partnership has historically benefited Synergy as many of the program's participants go on to become regular members of the health club.

Since this type of exercise programming mimics the widely accepted and often reimbursable phase II-III cardiac rehabilitation model, insurance companies should begin to consider similar reimbursement structures for the oncology patient population. More research is needed to demonstrate the efficacy of exercise programs on outcomes such as return to work and performance of activities of daily living.

In spite of the fact that the wellness programs do not

generate revenue directly, the benefits demonstrated by the programs far out-weigh the financial risks. Many patients have chosen to receive their cancer care at Exeter Hospital, or have transferred their care to Exeter Hospital, based on the availability of its extensive support programming or the recommendation of former patients. In addition, the oncologists and surgeons feel these services assist their patients significantly in the process of completing and recovering from cancer treatment, which can often be debilitating.

Programs seeking funding should investigate grant opportunities that may be available. Other sources of funding may include a fee-for-service format or a local, facility-specific fundraiser such as an annual walk, bike race, or 5-10K races. Once funding, staffing, and target population are established, staff education is the next critical step.

Community cancer centers affiliated with a rehabilitation department should consider collaboration. Such a partnership offers the highest level of expertise for patient assessment and individualized exercise prescription. In addition, this medically-based model allows for the safe management of patients with complex medical histories and various diagnoses and stages of disease. The partnership extends throughout the patient's cancer experience including preventative, restorative, supportive, and palliative phases of rehabilitation and includes specialized services such as lymphedema management and palliative care. It also allows for a more seamless transition between levels of care such as from hospitalization to home health care and ultimately to outpatient services and vice versa. Once discharged from physical therapy and/or the Cancer Well-fit™ exercise program, many of our patients become members of the fitness center in order to continue their exercise program.

“There is increasing evidence that exercise not only benefits patients from the perspective of their well-being, it also appears to have an effect on reducing cancer recurrence rates and improving survival,” said medical oncologist, Danny Sims, MD.

Survivorship is now possible for a greater number of individuals diagnosed with cancer than ever before, and many patients with advanced disease have treatment options well beyond first-line therapy. Management of disease and treatment-related side effects has become an important focus in quality oncology care. With carefully planned and implemented wellness programming, community cancer centers can expand and enhance the supportive component of the care they provide.

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