

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

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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.

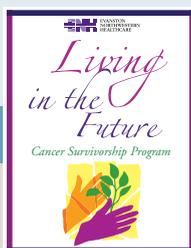
Physicians Identified for Monitoring Toxicity, Recurrence, and Second Malignancies

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.

References

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