

Survivorship Services— We Owe it to Our Patients!

BY MARY ANN HEDDON, RN, MSN, OCN

Staff at Pearlman Cancer Center, Valdosta, Ga., is continually challenged to identify the qualities and services that set us apart from our competitors. We recognized that taking the lead in developing a cancer survivorship program was one way to distinguish our organization as an early adopter of this essential service line.

As luck (or providence) would have it, my administrator ran across a flyer for the City of Hope's upcoming *Survivorship Education for Quality Cancer Care*. The City of Hope, under a grant from the National Cancer Institute (NCI), was offering a series of courses to educate oncology providers in teams of two from across the country. The goal: to provide education on cancer survivorship that would result in the development of programs to improve the post-treatment care for cancer patients in the U.S.

As the clinical trials coordinator, I was selected along with our education coordinator to attend the second of four annual conferences at the City of Hope in July of 2007. It was an eye-opening, challenging experience that left us with a sense of urgency to develop a survivorship program for our patients.

Fueled by excitement and oblivious to the true scope of our mission, we began work on the project immediately. We discussed the need for a survivorship program with our leadership. They were on board with the concept, but realistic about the prospects for funding an FTE to run the program. Undaunted, we mapped out what we thought represented an ideal

survivorship program and began developing each component in earnest. Over the next three years, we crafted a program on paper that we felt would serve the major physical and psychosocial needs of our patients as they transitioned "from cancer patient to cancer survivor."

It Takes a Village

We live in a community with a state university (Valdosta State University, VSU) that has a College of Nursing. We teamed up with one of the nursing faculty who incorporated the development of our psychosocial patient education handouts into the curriculum of her senior-level Nursing Research class. The students did a beautiful job creating these materials and, in the process, received meaningful real-world experience.

Working with our academic partner, we conducted a baseline needs assessment of our current cancer survivors, analyzed results, published several articles, and presented at several national conferences.

VSU also has a Division of Social Work that offers a Masters Program. We worked with a senior MSW student to create an evaluation plan to measure the effectiveness of educating our survivors on multiple aspects of physical and emotional well-being, as well as healthy choices in nutrition and physical activity. This work was accomplished during a year-long internship at our cancer center, during which the MSW student satisfied her course requirements, earned academic credits, and helped craft a critical component of our survivorship program.



Collaborations between healthcare organizations and institutions of higher learning are mutually beneficial and stretch limited resources.

Sharing Our Knowledge

As we progressed in our program development, we were struck by the magnitude of the undertaking and the realization that other cancer centers across the country would soon face the same monumental task. We discussed the idea of assembling our survivorship program into a "kit" and offering it to other cancer centers as a blueprint for developing their own survivorship program.

We partnered with our regional cancer coalition, which underwrote the mass printing of two program brochures and the purchase of four key publications. In exchange, we would share our kit with the three other cancer centers in the region. Next, we turned our attention to making the kit available for purchase by cancer centers outside our region. We talked with our administrative leadership, and worked out the details of how to structure a commercial venture. The result is the *Pearlman Survivorship Kit*. The original files for all program elements are included, allowing each cancer center to customize the kit to fit its unique resources, capabilities, and vision. The kit is available for purchase online at www.pearlman-survivorshipkit.com.

The Pearlman Survivorship Kit

The kit is divided into four booklets. Book 1 contains six scripted PowerPoint

presentations to educate staff, administration, physicians, survivors, and primary care providers. Photos of cancer center staff and patients can be added, along with the organization's logo. A Survey of Needs is included to allow cancer programs to survey and identify the unique needs of their patient population. The survey can be repurposed to assess the level and sources of distress in patients completing treatment. This Post-Treatment Needs Assessment serves as a baseline for transition into survivorship. If programs choose to offer a Survivorship Clinic, responses can guide the conversation and education at that appointment.

Also included in Book 1 is a template for a comprehensive, yet compact, Survivorship Care Plan and the shorter Treatment Summary, which can be paired with a care plan such as Journey Forward or the **LIVESTRONG** Care Plan. These two components can help meet the American College of Surgeons 2012 Program Standards 3.2 (Psychosocial Distress Screening) and 3.3 (Survivorship Care Planning).

For cancer centers electing to conduct survivorship education in a group setting, Book 1 includes a class syllabus and PowerPoint presentation developed by a multidisciplinary team. It's a two hour class that starts with a patient video, addresses known physical and psychosocial issues experienced by survivors, and includes a questionnaire about nutrition, physical activity, and several quality of life issues. A post-questionnaire can be administered six months to one year later to help assess the effectiveness of the class in modifying behaviors known to impact risk of recurrence.

Book 2 contains patient education handouts on 79 survivorship issues. They're color-coded by domain addressed—physical, social, psychological, spiritual, and an "other" category. Responses on the Needs Assessment, which parallels the education sheets, can guide selection of the education materials for each patient completing treatment.

Book 3 focuses on survivorship

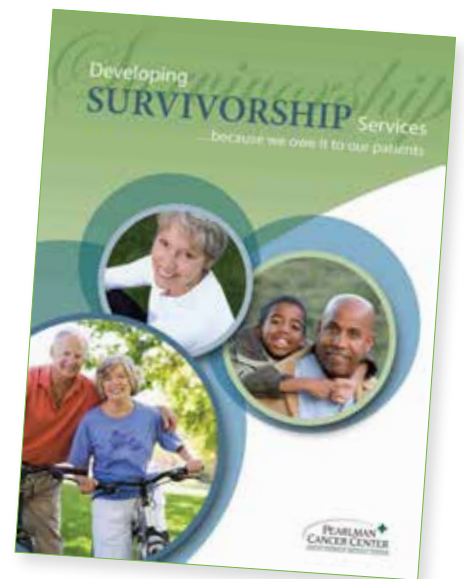
program resources. Suggestions for organizing a series of six Survivorship Workshops for the community are included. Presenters are selected from experts in the cancer center and surrounding area, such as physicians, nurses, dietitians, exercise specialists, mental health professionals, attorneys, and Social Security personnel. Other components in Book 3 include:

- A cancer rehabilitation program that uses existing cardiac rehab facilities. Staff are cross-trained using the Cancer Exercise Specialist program or a similar program, and no additional equipment is required.
- A guide to available print and online resources to help cancer centers build their library for staff and patients.
- A budget template in *Good, Better, Best* format, which allows facilities to tailor their program to available resources.
- A selection of potential funding sources to augment the financial support of a new survivorship program.
- Tools to share with primary care providers in the community. In the shared care model, longer-term survivors are transitioned to their primary care providers as oncologists focus their efforts on the acute needs of newly diagnosed patients. These tools help primary care providers to target their assessment on the late effects associated with the specific treatment received and common health problems experienced by survivors. Recommendations from the American Cancer Society are included as the standard for educating survivors on healthy choices in nutrition and physical activity.

Book 4 contains an evaluation plan that can be used when applying for a grant to bolster program funding.

Our Survivorship Program

Pearlman Cancer Center hired a FTE nurse practitioner in 2011 and opened its Survivorship Clinic in February 2012. We chose a consultation model and used selected components of the kit to quickly get our program up and running. Briefly, here's how our program works.



Patients completing treatment are shown a video about survivorship and asked to complete the Post-Treatment Needs Assessment. We create a Treatment Summary and Care Plan for the patient and pull together education sheets related to the issues self-identified in the Needs Assessment. The patient meets with the nurse practitioner for an hour in the clinic to review the Treatment Summary and Care Plan and discuss recommendations for nutrition and physical activity in the post-treatment phase. Eligible patients are offered a free 12-week cancer rehabilitation program. Patients then see the dietitian and social worker to round out the Survivorship appointment. Follow-up appointments are made, depending on the patient's needs.

It's no surprise that feedback from the patients is very positive. We're giving them the tools and structure they need to go forward and be a successful survivor. While it's certainly true that many patients choose not to make important choices that decrease their risk of recurrence, a new cancer, or other chronic illness, we're meeting a critical need to provide the information that gives each survivor a fighting chance to experience quality of life after cancer. **📺**

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