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Mapping the Journey

BY LACEY MEYER

Survivor care plans point the way to a healthy future.

Diagnosed with stage 3 breast cancer in 1997, Pam Cofer, now 54, developed arthritic nodules in her hands within six months of completing chemotherapy. She also underwent four back surgeries and a hip replacement because of arthritis during 2005 and 2006, and in 2008 she had an abnormal stress echocardiogram.

The Utah nurse and co-founder of the nonprofit Journey Beyond Cancer (www.journeybeyondcancer.com) says the physical issues didn't make sense—she was active and, before cancer, healthy. So Cofer began researching, which led her to Patricia Ganz, MD, an oncologist at the Jonsson Comprehensive Cancer Center at the University of California, Los Angeles, who specializes in long-term and late effects of cancer.

After taking a history of Cofer's treatment, Ganz explained to her that chemotherapy had induced chemical menopause. This caused Cofer's genetic predisposition for arthritis to advance rapidly instead of slowly over 30 or more years. Ganz also referred Cofer to a cardiologist who diagnosed her with diastolic dysfunction, a late effect of some chemotherapy drugs in which the heart doesn't completely relax between contractions.

Ganz prepared a survivorship care plan for Cofer that outlines specific recommendations for managing late effects and for routine screenings to monitor for future cancers. Cofer returned to Utah and met with her primary care physician, who was more than willing to confer with Ganz about Cofer's health and to complete the tests outlined in the survivorship care plan, including echocardiograms and blood work.



Lymphoma survivor Ben Tang follows a survivorship plan designed specifically for him. Photo by Kristene Che

“They decide together on the next course of action,” Cofer says. “My heart problem is a ‘cutting-edge diagnosis,’ according to my cardiologist, and my primary care physician understands strongly the importance of working with the team.”

With more cancer patients living longer, follow-up care will move to primary care physicians, lifting the burden currently placed on the decreasing number of oncologists. But this shift also requires that the physician and the patient understand the complex and unique challenges facing cancer survivors.

According to the 2005 Institute of Medicine report, “From Cancer Patient to Cancer Survivor: Lost in Transition,” oncologists should provide every patient with a treatment summary and follow-up plan to monitor for long-term and late effects, recurrence, and new cancers. According to a recent article published in the American Journal of Nursing, almost 75 percent of survivors experience long-term and late effects, in part from the treatment for first cancers that may cause additional health problems such as osteoporosis, cataracts, and diabetes.

The Plan

While a number of cancer centers have developed their own care plans, no single plan or approach has been adopted as the standard of care, and oncologists do not routinely generate them, says Kenneth Miller, MD, director of the Connecticut Challenge Cancer Survivorship Clinic at Yale Cancer Center.

Miller encourages patients to ask their cancer doctors for an end-of-treatment summary that includes the diagnosis, treatment, and specifics as to what they should do next. Patients should also ask for a question-and-answer session where they take notes.

Another option would be for the patient to request a copy of his or her medical records, which may have a fee attached but will give detail on drugs, dosages, and specifics about diagnosis. Patients can also print off any of a number of plans created by various organizations and available online, including the American

Society of Clinical Oncology's web-based plan.

Since patients see their oncologists during the transition from active treatment to survivorship, Miller says, they should get the care plan before returning to their primary care doctors. "It's really sort of saying where have you been, where are you now, where are you going, and how can we help you," he says.

Miller tells the story of one patient who came to him 15 years after an initial breast cancer diagnosis with cancer in the other breast. "When we tried to get old records, it turned out they had been destroyed," Miller says, and the patient couldn't remember the drugs she had taken. "So when we had to make decisions about treating her, it was more complicated because we had to make an educated guess as to what chemotherapy she had actually received."

Ben Tang, 44, diagnosed with non-Hodgkin lymphoma in 2005, learned about care plans at a survivor event at UCLA two years after treatment. Tang says the plan that Ganz created gives him confidence by helping him understand his treatment. "And it gives you some piece of mind knowing that you're following the correct procedures for looking out for what could be some very serious complications as a result of all the treatment that we've gone through," says Tang, who was treated at two different cancer centers and still sees both oncologists and his primary care physician. All three now collaborate on his care.

So far, Tang says he has had some "little, nagging" side effects, such as neuropathy, gastrointestinal issues, and leg cramps. Despite these and a slight heart dysfunction that showed up on his echocardiogram, he says he feels "really good."

Given his extensive treatment—chemotherapy, stem cell transplant, radiation—he knows there could be more issues to come. "There are definitely a lot of things that I know I need to keep an eye on that show up in these more specialized tests."

More Than Medical

A care plan may also include issues outside those of possible future physical issues. For example, Ganz recommended genetic counseling for Cofer and her 24-year-old daughter.

Miller says doctors should also emphasize the continued importance of nutrition and exercise, which can become undervalued in light of the cancer experience, especially when there is evidence they can impact the development of secondary cancers—and in some cases recurrence. "With that in mind, it's, in a sense, our responsibility to really promote a healthy lifestyle and to give specific information on how to do that," he says.

According to Brad Zebrack, PhD, a professor of social work and public health at the University of Michigan, there are also psychological and social components that need to be included in a care plan. He says that studies suggest upwards of 30 percent of childhood cancer survivors experience symptoms of post-traumatic stress or depression.

"Long-term survivors of all ages continue to have psychological and social

challenges many years after their diagnosis and treatment,” says Zebrack, a 23-year Hodgkin disease survivor, who emphasizes that nurses, social workers, and psychologists all have a role to play in survivors’ long-term care.

Although the survivorship care plan is relatively new, both Cofer and Miller recognize its importance and benefits and look forward to it being adopted as a standard of care in the future, which Miller predicts will happen as health care providers move to electronic medical records.

“I want the best quality of life while I’m here,” Cofer says, “and so it’s important that survivors know the effects of these treatments and get the best care that we can have.”