



A care plan should be guided by the patient's expressed goals and desires for life after treatment.

## Collaborative care plans for posttreatment cancer survivors

Helen H. Miller, LCSW, ASW

In the 1970s, less than 50% of people with cancer lived 5 years or longer after their diagnosis. Today, that statistic has increased to nearly 70%. Although there are now more than 12 million US posttreatment survivors, researchers are only beginning to study the long-term effects of cancer on all aspects of a person's life.

Since the Institute of Medicine released its report, "Cancer Patient to Cancer Survivor: Lost in Transition," in 2006, the Survivorship Care Plan has emerged as the standard of care for post-treatment survivors. Organizations and agencies such as the American Society of Clinical Oncology (ASCO),\* National Cancer Institute (NCI),† and CancerCare‡ are raising awareness among patients and professionals about the need to craft a detailed plan that addresses both a patient's medical and psychosocial needs.

A comprehensive Survivorship Care Plan includes a treatment summary that contains details such as the patient's date of diagnosis, type and stage of cancer, treatments received, and any complications experienced. It also includes a follow-up plan describing the

patient's state of health at the end of treatment, schedule of future visits (date, time, and with whom), and tests that will be done as well as why they are needed. Potential long-term side effects and symptoms to watch for should also be discussed with the patient.

One important aspect to keep in mind when crafting a Survivorship Care Plan is that it shouldn't be prepared for the patient and based solely on his or her medical history and needs. Rather, it should be crafted in conjunction with the patient and guided by that person's expressed goals and desires for life after treatment.

We recently met in our offices with a post-treatment survivor named Barbara Draimin, DSW. Barbara is a co-founder of a New York City-based nonprofit organization that provides support for people affected by HIV/AIDS and cancer. Despite a background rich in social work and patient support, she turned to CancerCare for support in 1989 when her mother received a terminal cancer diagnosis and again more recently, when Barbara was given diagnoses of ovarian cancer and then non-Hodgkin lymphoma a few years later.

Barbara's experiences as a post-treatment survivor provide an interesting snapshot of the challenges faced when putting together a Survivorship Care Plan. Her situation also demonstrates how a patient and health care professional can work as a

\* See ASCO's Web site for posttreatment survivors at [www.cancer.net/patient/Survivorship](http://www.cancer.net/patient/Survivorship).

† See NCI's Office of Cancer Survivorship Web site at <http://dcccps.nci.nih.gov/ocs>, as well as their various survivorship publications, including the Facing Forward series.

‡ See the CancerCare Connect booklet "After Treatment Ends: Tools for the Adult Cancer Survivor" at [www.cancercare.org/pdf/booklets/ccc\\_survivor.pdf](http://www.cancercare.org/pdf/booklets/ccc_survivor.pdf) or learn about our services for posttreatment survivors at [www.cancercare.org/get\\_help/special\\_progs/post\\_treatment.php](http://www.cancercare.org/get_help/special_progs/post_treatment.php).



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Clinicians see what occurs internally, but only patients know what happens externally in daily life.

team to produce a follow-up plan that satisfies both the medical and the emotional needs of the person after treatment.

Barbara describes that she did not receive a formal treatment summary when she completed treatment and instead had to piece together her own two-page synopsis to share with a new internist. “It’s really hard to put a treatment summary together retroactively,” says Barbara, “either because of the chemobrain or because you just don’t want to remember.”

Oncology nurses can help patients avoid this situation by ensuring each patient receives a summary upon completion of treatment<sup>§</sup> (recommended survivorship care plan templates are available from several organizations) or, at the very least, by encouraging patients undergoing active treatment to keep detailed records of appointments, treatments, medications, and surgeries. Many organizations, such as the Lance Armstrong Foundation,\*\* provide binders and forms to help patients keep track of such information.

One thing Barbara did receive after her treatment ended was the date and time for a follow-up appointment. While this information is critical, it would be more beneficial for the patient if a member of the health care team could take time to sit down with the patient as the end of treatment nears in order to collaborate on a plan of action.

**T**he Survivorship Care Plan templates mentioned earlier list the recommended follow-up tests and schedules. However, these should not be the end-all-be-all recommendations. Instead, they should serve as a starting point for conversations about a patient’s wishes for his or her life after treatment. A person’s answers to questions such as

“What is meaningful or important to you?” and “What are your personal goals?” should guide plans for how the health care team will continue to monitor him or her.

For example, a patient with young children may opt to have checkups and screenings more often than typically recommended so that aggressive treatment can be prescribed at the first sign of recurrence. A patient who battles anxiety may feel better—or perhaps more anxious—being monitored so regularly. Or, your patient may be more like Barbara, who wishes to avoid a constant battery of tests and focus more on living her life.

Barbara says that during discussions about her follow-up care, she was open with her health care team about her wishes, telling them: “My goal is to be as healthy as I can be and to live as rich a life as I can.” In fact, she says, her plans were to travel around the world “scans or no scans.”

When symptoms of recurrence showed up and her new internist suggested she preemptively undergo chemotherapy, Barbara communicated that she’d rather wait until the results of her normal 6-month evaluation came in before embarking on another round of treatment. She chose to go this route because, she says, “During my initial chemotherapy, I lost my quality of life completely.”

Barbara and her physician have truly been partners in survivorship care planning. “We worked together to design a follow-up plan that we both feel good about,” says Barbara. And each year, patient and doctor sit down together to revisit the plan to see where things stand, both in Barbara’s life and in the course of her disease. After all, as Barbara notes, the health care professionals may know what’s going on internally, but only the patient knows what’s going on externally in his or her day-to-day life.

Health care professionals who allow their patients the opportunity to collaborate on the Survivorship Care Plan improve their patients’ quality of life by providing them with tremendous service. ■

§ Helpful tools exist for professionals, such as the Journey Forward Survivorship Care Plan Builder (download at [www.journeyforward.org](http://www.journeyforward.org)) and ASCO’s Survivorship Care Plans for Breast and Lung Cancer (download at [www.cancer.net/patient/Survivorship/ASCO+Cancer+Treatment+Summaries](http://www.cancer.net/patient/Survivorship/ASCO+Cancer+Treatment+Summaries)).

\*\* The LIVESTRONG Guidebook can be ordered at [www.livestrong.org](http://www.livestrong.org).

Helen Miller is the CEO of CancerCare