

## TRANSITIONS

# Prescription for Living

BY MELISSA GASKILL

*Nurses' research article helps pave the way for essential medical care after cancer*

Betty Ferrell, research scientist at City of Hope National Medical Center in Duarte, Calif., and an oncology nurse for 30 years, has seen the scenario countless times. Someone walks in for that last dose of chemotherapy, and everyone is ready to celebrate. But inside, the about-to-be-former cancer patient is terrified. The patient is glad to know this is the last treatment, of course, and participates in the party. But it's hard to shake the fear of what lies ahead.

Thanks to advances in treatment, more than 10 million Americans are cancer survivors, and they face unique challenges. “Long-term survivorship wasn't an issue when I entered oncology nursing,” says Ferrell, PhD, RN. “It's a great new problem to have.”

But it's a problem nevertheless.

In 2006 the Institute of Medicine issued the report “From Cancer Patient to Cancer Survivor: Lost in Transition.” The phrase ‘lost in transition’ was used because that's how survivors say they feel, says Ferrell, who served on the IOM panel that wrote the report. “In the process of laying out the issues, we addressed the fact that people now live a long time after cancer, but often have ongoing effects,” she says. “We kept hearing over and over that there is no continuity and no ongoing care. You don't have cancer anymore, so you go back to your regular doctor. But it is not uncommon for people not to know the names of the drugs they received and the possible delayed effects.”

### Easing the Transition

In light of the difficulties of this transition, the IOM report recommended that individuals leave the cancer setting with a care plan that summarizes diagnosis, treatment received, potential long-term effects, ongoing health issues, and systems of care to meet the individual's specific needs. In response, a number of organizations gathered to look at implementing this survivorship planning, and as part of these efforts, five nurses wrote an article and a model plan published in the April issue of the *American Journal of Nursing*.

Dubbed “A Prescription for Living,” the model plan — a fill-in-the-blanks document where patients or healthcare providers can record a person's cancer and treatment history and post-cancer care needs — is intended as a starting

point for survivors to talk to providers.

“If there is a blank, people feel obligated to fill it in,” says Pamela Haylock, RN, a cancer care consultant and one of the five nurse authors of the plan. “There are suggestions of wellness planning, exercise or physical activity, nutritional issues, weight management and cancer screenings. It also covers possible delayed effects to watch for.

“For example, lots of people who had radiation have skin lesions, so their skin needs to be monitored,” Haylock adds. “The plan considers what sorts of second cancers are common and how to monitor for those, as well as things like who is likely to be affected by infertility and what can they do. The blanks on the form cue people to discuss these kinds of issues.

Print out and take the form to healthcare appointments for updating, Ferrell suggests. “The take-home message is that you are a survivor, and we’re glad, but we know your needs will be ongoing and you deserve to have attention to those ongoing needs.”

Haylock likens completing a plan to an exit interview from a job. “It is kind of a quality assurance effort, what did we do right, what could we have done better, and here are some things that people can do as they go out into what many refer to as their ‘new normal’ life.”

While this planning can be done with the aid of doctors, nurses or social workers, a common assumption is that nurses will take the lead. “Nurses can go through these things with the person and provide them with that safety net, reassure them that they can still call and we’ll help them find the right resources,” Haylock says. “Survivors tell us that it is such a scary time. They have been going to the doctor regularly and now they don’t have that anymore. It is tremendously helpful to know that a nurse will still be there for them.”

Nurses are most likely to be able to spend the time working with a patient on a survivor plan. “Some doctors express concerns that this is not a reimbursable activity,” says Haylock. “But nurses have been able to wrap some of the time spent on the plan in with other office procedures that are reimbursable.” This issue of time is one reason the *American Journal of Nursing* template is brief, one page front and back, she adds. “It probably won’t cover every need, but it is a beginning place for discussion. Some patients will be informed enough to fill in a lot of it themselves.”

While the IOM recommends that this planning be done at the end of treatment, Haylock and others suggest it could also start at the beginning. Either way, survivors should expect someone knowledgeable to work with them on developing a plan, says Diana Mason, PhD, RN, editor-in-chief of the AJN. “Copy the form. Ask people to fill it out, to help you write down a summary of what you’ve been through, and what you need to do from here on out,” she says. “Ask what you need to know and what you need to communicate to other providers.”

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## The Plan's Root

The *AJN* model plan drew from one in use for about three years at New York City's Memorial Sloan-Kettering Cancer Center. That plan is provided to patients on their first visit to the Survivorship Clinic, says Mary S. McCabe, RN, director of the facility's survivorship program. When patients complete treatment, a copy is provided both to them and their community physician.

“It serves as a communication link so everyone has the same game plan,” says McCabe. “It has to be customized to the individual and reflect the treatment that they received. The issues that you discuss with an 85-year-old prostate cancer survivor, for example, are different from those for a 35-year-old breast cancer survivor.”

It's also important for survivors to be aware that the care plan is not a static document but will need to be updated periodically. “As we learn more about the long-term effects of our newer treatments, and as we get better at reducing and eliminating the post-treatment problems that survivors face, we will want survivors to benefit from this new information,” McCabe says.

Nancy Houlihan, MA, RN, clinical nurse specialist in Memorial Sloan-Kettering's survivorship program, says any good survivorship plan has two parts, treatment and care. The former includes the detail of every treatment received, pathology of the tumor, name of any surgeries, names and doses of drugs, type and dosage of radiation, and site given. These all may have an impact long term on overall health.

The care part of the plan looks at what a person needs to incorporate going forward as a result of the cancer and treatment, including testing and screening, and health behaviors that can reduce risk of other cancers or other diseases. “For example, studies show a low-fat and high-fiber diet and daily weight-bearing exercise can reduce risk of cancer and of other diseases,” Houlihan says. “So that should be in there, as should any other risks, such as if a person has had high sun exposure, they need skin cancer screening.”

At Memorial Sloan-Kettering, nurse practitioners help patients prepare their plan. It is very time-consuming, says Houlihan, and that is one of the barriers to widespread use.

“Oncologists certainly believe this is important, but they just don't have the time. We are having discussions about how to do this better.” A key step would be providing reimbursement for the time healthcare providers spend on a plan.

Other options are electronic versions, which would also allow for easier updating, or forms standardized by type of cancer, where individuals just add their

personal information. Both would reduce the time needed to complete a plan.

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—Pamela Haylock, RN

## Help Yourself

Meanwhile, the Prescription for Living care plan was designed to include individuals in their own planning for future care. “The individual is central to it,” says Houlihan. “That is a very important message in taking care of cancer survivors.”

Haylock agrees that many survivors can use this plan as a tool to partner with their healthcare providers. “There are lots of things you can use, but this is a one-page summary you can take to the next doctor or new city. We included space for physicians’ names so contacts can be made quickly and easily.”

Many healthcare providers have lived for the day where more and more people are survivors, says Haylock, but hardly anyone realized all the things those survivors would face. “Lots of survivors have pointed out that trying to figure out the ultimate long-term effects [of cancer and treatment] is a moving target. They do need a lot of support, and we’re only beginning to understand the complexity of their needs.

“It’s been really thrilling to watch the changes, and we’re at a good place. But we have a lot more work to do.”

The plan’s developers hope survivors will help them fix that target in place. “If people use this and it ... doesn’t meet their needs, we hope they will tell us and we can revise it,” Haylock says. People are also welcome to revise it on their own, and at least they don’t have to reinvent the wheel.

Survivors should feel free to modify the plan, Mason agrees. “This is a first pass; it’s not set in stone. But be pro-active and hold healthcare providers accountable for helping. Survivorship planning will happen when survivors begin to demand conversations about how they can live with cancer, and when they refuse to leave until this is filled out.”