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# COUNTING THE DAYS

BY MELANIE FRIDL ROSS

## UF CANCER SURVIVOR PROGRAM HELPS PEOPLE TRANSITION FROM PATIENT TO SURVIVOR

**O**ur lives revolve around our calendars. Soccer games, client meetings, birthdays — they fill the pages of our Day-Timers and PDAs.

With a diagnosis of cancer, the normal daily routine is replaced by a whole new rhythm. Patients shuttle from appointment to appointment. From oncologist to surgeon and back, week by week navigating countless visits for tests and treatments.

When it all eventually ends, the calendar takes on a new role: Tracking the days and, hopefully, decades that pass without recurrence.

The benchmark has always been five years. But as medical scientists learn more about the many diseases we collectively call cancer, survival takes on a whole new meaning — and offers new challenges and opportunities for doctors and patients.

"There basically needs to be a paradigm shift from seeing cancer as an acute illness that in the past often resulted in death to seeing it as a chronic condition," says Michelle Bishop, a research assistant professor in the Division of Hematology/Oncology at UF's College of Medicine. "And so right off the bat we have to be thinking about this very differently. Cancer survivorship doesn't just end after treatment."

Susan White has been counting the days since March 7, 2007, when she strode into Shands at the University of Florida and began a long odyssey marked by breast cancer surgery, four months of chemotherapy, six weeks of radiation and visits to a physical therapist.

Since then the calendar has become her touchstone. She's marked the one-year anniversary of her operation, counted

the days she's been cancer-free. Yet it's a strange time, one that, like many patients, she finds herself ill-equipped to handle.

"Now that I'm at the end of my treatments, I've walked to the end of the hall and there's a door with nothing past it," says White, 53, assistant director for special projects at UF's College of Public Health and Health Professions. "Where do I go from here? Who's my doctor? I completed treatment at the end of October. Every three months I go for a mammogram, every year an MRI. You don't realize when you enter it how long a process it is. You just have no clue all the stuff you have to go through."

"You end up at the end of treatment really not knowing where you stand. You know you survived it; for all apparent purposes you don't have anything right now. But the biggest fear I heard from fellow survivors is that with every little ache and pain you think 'I must have cancer in my toe.' You're constantly waiting for the other shoe to drop. You just wonder is anybody watching out for me close enough? I wish there was a physician that I could call on that could be sort of my clearinghouse, to ask 'Is this something we need to worry about?'"

White isn't alone. Nearly 11 million Americans are cancer survivors, up from just 6 million in 1986, according to National Cancer Institute statistics. Of those, 270,000 are young adult survivors of childhood cancer. In Florida, about 97,000 cases are diagnosed each year, and about two-thirds of the adults and more than 75 percent of the pediatric patients will live long-term. That's tens of thousands of people who are living proof of the increasing effectiveness of treatment, but who also grapple with uncertainty.



Sarah Kietrys

## LOST IN TRANSITION

The National Cancer Institute established an Office of Cancer Survivorship in 1996, citing the “unique and poorly understood needs” of many cancer patients. And in 2005, the Institute of Medicine published a seminal report on cancer survivorship subtitled “Lost in Transition.” The document outlines the lack of follow-up for the long-term consequences of treatment and provides recommendations for how patients should be monitored in the years after their diagnosis.

That’s especially important because cancer survivors must be tracked closely for what pediatric oncologists were the first to call the “late effects” of therapy — complications such as impaired growth and development, problems with vital organ function, infertility or hormonal disturbances, or the threat of a second malignancy. Many breast cancer survivors, for example, experience fatigue or problems with weight gain or memory loss. Survivors of both childhood and adult cancer struggle with osteoporosis, heart problems, depression, infertility or the anxiety associated with the fear of recurrence.

In response, UF practitioners affiliated with the UF Shands Cancer Center are launching the UF Cancer Survivor Program this summer — the only program in the

United States designed to care for survivors across the entire age spectrum, from children to adolescents to senior citizens. Any cancer survivor who is off therapy for at least two years without evidence of disease will be able to participate, said Program Director Patricia Shearer, a pediatric oncologist who spearheads the effort full-time.

“The reason we need a survivor program that spans the age range is that many so-called late effects of therapy don’t occur for many years after completion of treatment, so patients first of all need a place to go and, secondly, patients of all ages need evidence-based recommendations of what to look for,” Shearer says. “Our program is set up to accomplish those objectives.”

UF physicians will see about 1,500 survivors a year in specially organized clinic visits, where they will undergo routine exams and receive individualized health information. This will include a treatment summary with the stage and type of cancer they had, the treatment they received (such as surgery, chemotherapy or radiation), information about possible late effects, and guidelines for follow-up care, such as referral to behavioral medicine professionals or other consultants. The goal? Patient empowerment.

Initially, the adult clinic will focus on survivors of breast cancer, lymphoma and non-Hodgkin’s lymphoma, with plans to expand to include two-year survivors of any adult-onset malignancy. All survivors of pediatric and adolescent cancer will be included from the beginning. Program staff will work to inform cancer survivors, practicing clinicians, fellows, residents, medical students, allied health personnel and the community about cancer survivorship issues.

“A huge component is just educating survivors as to what they are at risk for and how to be screened for those risks, and educating primary care physicians on how to take care of survivors in the special way they need to be cared for,” says Merry-Jennifer Markham, a specialist in adult hematology/oncology who will direct the program’s adult component.



# CLOSING THE GAP

UF clinicians are especially interested in reaching young adult survivors of childhood cancer ages 21 to 30, because they are often no longer under the care of a pediatrician but have not yet established a relationship with a primary care provider or adult oncologist. Many cancer patients seem to get lost in the switch from patient to survivor, from the point of being on treatment to being off treatment.

"A lot of oncologists follow patients up to the five-year mark. Once they reach that mark, patients often are discharged back to their local primary care physician," Markham says. "A lot of these late effects often don't manifest until after the five-year mark. There is a sort of transition period where patients are really not being followed for the effects of the therapies."

UF researchers are collaborating with Paul B. Jacobsen, chair of the Department of Health Outcomes and Behavior at the H. Lee Moffitt Cancer Center and Research Institute in Tampa, to set up research projects and share data.

"We're trying to make sure we restore people to as full health as possible," Jacobsen says. "Until recently, there have really been no coordinated methods for caring for these people. The vast majority are going to live for many, many years. Our focus is on how well they are doing in the post-treatment period, and how can we make sure we're doing whatever we can to prevent recurrence of cancer and the development of new cancers. We're also conducting surveillance, so if there is a recurrence of cancer or a new cancer we will detect it in the early stages."

In the pediatric survivorship arena, evidence-based guidelines from the Children's Oncology Group, a consortium of more than 200 institutions, are already used in 35 centers around the country. UF physicians hope to apply a similar model to adult cases.

A recent study published in the *Journal of Clinical Oncology* observed preventive care patterns in adult cancer survivors. Survivors who saw both a primary care provider and an oncology specialist were most likely to receive both general health and cancer screenings, whereas those who saw a primary care provider only were most likely to have cholesterol checks and bone densitometry. With time, cancer screenings decreased as oncologists became less involved and more focus was placed on primary care only.

"It looks like transfer of responsibility for these preventive services to the primary care provider is not happening," Bishop says. "Either way there was essentially a gap in getting the comprehensive care. There needs to be better communication between those providers."

Mary Ann Burg, a sociologist in UF's Department of Community Health and Family Medicine, is working on prototypes of survivor transition plans and has funding from the Florida Breast Cancer Coalition to test them in the field, using focus groups comprising oncologists, primary care physicians and breast cancer survivors.

The idea? To ease the way for patients like Susan White.

In the weeks after her treatment ended, White's thyroid quit. She was having symptoms but didn't know what was causing them and whether she should make an appointment to see her cancer doctor or her general practitioner.

"As a cancer survivor, you don't know what part of your body is in the cancer world and which part isn't in the cancer world," says White, who ended up seeing her oncologist and undergoing blood tests that revealed her thyroid was malfunctioning.

White says she expects the new program will benefit patients like herself who are working hard to get back to the business of living in the wake of so much poking and prodding, so many months of doubt.

"People ask me all the time, 'What's your prognosis?'" she says. "I don't know. But I'm alive today." ☒

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One year anniversary of surgery

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