

Cancer Care Seeks to Take Patients Beyond Survival



J. Emilio Flores for The New York Times

RECOVERY

Tanya Saunders survived cancer but suffers effects of her treatment.

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Published: May 22, 2007

As a growing number of Americans are learning, surviving cancer can mean slipping into a rabbit hole of long-term medical problems — from premature menopause and sexual dysfunction to more debilitating side effects of chemotherapy and radiation, like heart disease and even new cancers.

The realization that cancer and its aftermath can go on for years has given rise to a medical specialty known as survivorship. At several major hospitals around the country, survivor programs financed by the Lance Armstrong Foundation are focusing on life after cancer.

“It’s no longer sufficient to say, ‘Well, you survived,’ ” said Mary S. McCabe, who directs the program at Memorial Sloan-Kettering Cancer Center in New York. “We need to maximize their recovery and quality of life.”

Cancer treatment and research are expanding to incorporate long-term postcancer care. With the number of survivors up to 10 million in the United States, from 3 million in the 1970s, cancer is increasingly being treated as a chronic disease, like diabetes or multiple sclerosis. As the presidential candidate John Edwards said in March after his wife, Elizabeth, learned that her breast cancer had returned and spread, the disease was “no longer curable” but “completely treatable.”

At U.C.L.A. Medical Center in Los Angeles, Dr. Patricia A. Ganz is helping patients like Tanya Saunders close gaps in their medical care. Staying healthy has become a full-time job for Ms. Saunders, who has endured one complication after another in the 15 years since she received her diagnosis of Hodgkin's disease as a college student.

Radiation and chemotherapy thrust her into menopause. After a recurrence and a second round of treatments, she developed congestive heart failure. Last year, the bone tissue in one of her hips collapsed, forcing her to undergo a hip transplant.

Now 36, Ms. Saunders takes 11 medicines a day. She exercises three days a week with other cardiac patients, sees a much-loved psychotherapist (who is treating her free of charge) once a week and takes pottery and sailing classes. She lives on disability payments and qualifies for Medicare.

“It’s a kind of a renewal of spirit I would say I’m looking for while I try to get my strength back,” Ms. Saunders said.

Another patient of Dr. Ganz’s, Karen Huner, credits her with diagnosing and treating the hypothyroidism that was causing exhaustion and headaches months after she was cured of breast cancer. Other doctors had told her that the symptoms were effects of chemotherapy and that she should “just get used to it,” said Ms. Huner, a 44-year-old yoga and pilates instructor. In fact, she added, it was the radiation she received that probably disrupted her thyroid function.

She recently developed lymphodema, the painful swelling and water retention that can happen in the arm where lymph nodes were removed.

“My lymphodema doctor said to me, ‘Be happy you’re alive,’ ” Ms. Huner said. “I almost strangled her.”

The potential side effects of radiation and chemotherapy have been known for years, especially among survivors of childhood cancers. But the big push for awareness and support followed a strongly worded report in 2005 from the Institute of Medicine, part of the National Academy of Sciences.

“The transition from active treatment to post-treatment care is critical to long-term health,” it concluded. “If care is not planned and coordinated, cancer survivors are left

without knowledge of their heightened risks and a follow-up plan of action.” Insurers, it added, “should recognize survivorship care as an essential part of cancer care.”

Another problem is that survivors may shy away from doctors, and not just because of the cost. Dr. Anna T. Meadows, a pediatric oncologist who directs the survivors’ program at the Children’s Hospital of Philadelphia, said people who got their diagnoses as children or teenagers were often wary of care that would force them to revisit a painful part of their past. These survivors do not necessarily need a cancer specialist for routine checkups and screening, she said, but rather someone who understands their previous treatment and its risks.

“A lot of cancer survivors have nothing wrong with them,” Dr. Meadows said. “But what is important is for anybody who’s had cancer is to know what treatment they received and what it’s likely to lead to in the future.” The program is adding two primary care doctors to encourage follow-up visits.

In the largest study so far of survivors of childhood or adolescent cancer, published last October in *The New England Journal of Medicine*, researchers documented a high rate of illness because of chronic conditions caused by life-saving treatments. The study tracked the health of nearly 10,400 adults now in their 20s, 30s and 40s who were treated for cancer between 1970 and 1986.

More than 62 percent of those survivors had at least one chronic condition; nearly 28 percent had a severe or life-threatening one. The survivors were more than three times as likely as their siblings to have a chronic health condition, and women were at greater risk than men. Survivors of bone tumors, central nervous system tumors and Hodgkin’s disease had the highest risk of a serious chronic condition.

The good news is that almost 80 percent of children and teenagers who get diagnoses of cancer today become long-term survivors. Moreover, treatments have changed to minimize the risks; the lowest effective doses of drugs and radiation are used.

“The silver lining of this is that we know what to expect a reasonable amount of the time,” said Dr. Kevin C. Oeffinger of Sloan-Kettering, a lead author of the report. While young cancer patients are more vulnerable to damage because their organs are still growing, Dr. Oeffinger said, the study has obvious implications for adults.

Age and type of treatment play a huge role in the experience of cancer survivors, several experts said. Many experience no side effects at all. Others, especially women of child-bearing age, face infertility and early menopause.

“Our research shows that younger patients have a harder time, both physically and emotionally,” said Dr. Ganz, of U.C.L.A. “It’s not something they’ve expected.”

At Sloan-Kettering, five social workers are assigned to concentrate exclusively on follow-up care for survivors. Part of the plan, at Sloan and other cancer centers, is to develop an online database of patient-care summaries — of the cancer treatment received, the potential risks and recommended follow-up care — that could be used by any physician. The hospital also plans to open an off-campus outpatient center devoted to cancer survivors' physical rehabilitation, in part with a donation from the media entrepreneur Robert F. X. Sillerman, who was treated at Sloan-Kettering six years ago for tongue cancer. He received chemotherapy and radiation and later began to suffer pain and muscle spasms in his shoulders and back, as well as increasing weakness in his left arm. Today, Mr. Sillerman said, he has reversed the damage with a little bit of medication and a lot of physical therapy. He exercises six days a week with weights, bands and manual resistance, partly with a personal physical therapist whom he puts up in a Manhattan townhouse adjoining his family's. He said he appreciated the fact that few have the same luxury.

"I was two years out from my cure before I was able to find the right protocol and treatment," said Mr. Sillerman, 59. "Our hope is to eliminate that and provide access to rehabilitation right away, initially in the New York metropolitan area and eventually to make that a template nationally."

For premature menopause in patients who can safely use estrogen, Dr. Mercedes Castiel likes to give teenagers and young women birth control pills to control hot flashes and bone loss. "It's nicer to say I'm on the pill like my peers instead of hormones like my grandmother," said Dr. Castiel, director of the Barbara White Fishman Women's Health Center at Sloan.

Even sexual dysfunction, which for years was viewed as a small price to pay for survival, is now treated like any other side effect. Vaginal dryness and missed or blunted orgasms are among the most common complaints.

"We look at it in terms of enhancing intimacy," said Dr. Michael L. Krychman, Sloan's expert on the subject. "They want things to get back to normal."