

The Informed Patient: Cancer Survivors Find Support

The Wall Street Journal

By Laura Landro

November 14, 2007

Tired and depressed after completing treatment for prostate cancer, Don Winslow found help from a program that offered yoga and tai chi classes, a poetry workshop, and a weekly support group for cancer survivors in Delmarva, Md., near his home. When his wife, Marion, was diagnosed with breast cancer two years later, she, too, signed up.

Like many patients seeking help for living with cancer, the Winslows didn't find it at their doctor's office. A newspaper ad led them to the free programs offered by the local chapter of the Wellness Community, a nonprofit group. And they learned of a common frustration among other survivors they met there. "Whether they were newly diagnosed or had gone through cancer and are surviving it, they don't know enough about what's going on, and they complain that their doctors never tell them anything," says Mr. Winslow, a 75-year-old retired chemical engineer.

As the ranks of cancer survivors grow to more than 10 million in the U.S., so does concern that medical providers aren't doing enough to link patients and families to resources they need to face the physical and psychological effects of cancer -- from fatigue and memory loss to depression, anxiety, sexual dysfunction and pain.

Now, leading cancer-advocacy groups, major cancer centers, insurance companies and oncology medical societies are stepping up efforts to help, with new programs to provide so-called psychosocial services that aid patients, families and health-care providers in managing the myriad psychological and social aspects of cancer.

The new push comes on the heels of a report last month from the Institute of Medicine, which includes models that providers of cancer care can use to identify psychological health issues and tailor services to patients' individual needs. While research has shown that the quality of life and adherence to medical regimens can be greatly improved by services such as patient education, support groups and counseling, the report said, health-care providers often don't understand patients' needs for information, don't consider psychosocial support an integral part of their care, aren't aware of resources in their own communities, and fail to recognize, adequately treat, or refer patients to services that can help.

"As a culture, medical practice has not embraced psychosocial care as a fundamental part of what it does," says Edward H. Wagner, a member of the IOM committee that prepared the report and director of Seattle-based Group Health Cooperative's MacColl Institute for Healthcare Innovation. "All too often cancer patients feel that their experience of care not only doesn't support them, but makes them suffer more than they needed to."

According to the IOM, part of the National Academy of Sciences, over the past two years the five-year survival rate for the 15 most prevalent cancers has increased to 64% from 43% for men and to 64% from 57% for women. Patients and their families can learn how to take advantage of free programs around the country that provide psychosocial support from the IOM report, "Cancer Care for the Whole Patient," available free from the IOM.edu Web site.

For patients treated at the 21 large cancer centers that are members of the National Comprehensive Cancer Network, more resources are often available. Houston's M.D. Anderson Cancer Center, for example, offers more than 75 programs, most free of charge, including yoga, meditation, acupuncture and expressive writing; it also screens patients for signs of psychosocial distress, using tools like the Distress Thermometer, which asks patients to rate their distress on a picture of a thermometer on a scale of 0-10.

But more than 80% of people with cancer are treated at local oncology practices and hospitals, "and they need to have access to the resources that exist in their communities but often aren't being fully utilized," says Kim Thiboldeaux, chief executive of the Wellness Community (thewellnesscommunity.org) and a co-author of "The Total Cancer Wellness Guide." With more than two dozen centers in the U.S., as well as affiliated programs in the U.S. and overseas, the group offers professionally led support groups, educational workshops and nutrition and exercise programs for people affected by cancer.

Ellen Dominguez, a 53-year-old writer in the human-resources department at Ernst & Young in New York who is fighting recurrent ovarian cancer, says she joined a Wellness Community online support group after hearing about it on a television program. While she sees fliers about support groups posted on walls at doctors' offices and in hospitals, medical professionals have never suggested one to her. "Maybe doctors don't feel it is within their boundaries to tell people about support groups," she notes. She has urged her own doctors, "Don't ever feel afraid to bring things up that might feel like treading in sticky waters."

One problem is that oncologists are generally reimbursed only for providing direct medical care, and aren't trained to look beyond treating the cancer itself. Primary-care physicians or others who may provide follow-up care typically don't have systems in place to screen for psychosocial problems or make referrals to community services. Because patients may feel embarrassed to ask for help when it isn't offered, that creates a dangerous "don't ask, don't tell" environment, says Patricia Ganz, a medical oncologist who also served on the IOM committee and is director of the Division of Cancer Prevention and Control Research at the University of California, Los Angeles. "All the doctor has to do is ask, 'How is your sex life?' and if the patient says fine, you don't need a big dialogue," says Dr. Ganz. "But when there is a problem, we need to address it, and if we never ask, a patient doesn't know they can talk to us about these topics."

UCLA is one of a number of centers around the country working with grants from the Lance Armstrong Foundation to offer survivorship consultations and care plans. UCLA's Vital Information and Tailored Assessment program offers patients a two-hour, one-time

consultation with specialists in cancer survivorship, billed to insurance as a regular visit with a physician, to identify posttreatment physical and psychological problems and create a plan for future treatments including wellness-enhancing strategies. The Fred Hutchinson Cancer Research Center in Seattle has a program targeted at patients such as bone-marrow transplant survivors who may face lifelong issues including memory loss and depression.

The Wellness Community, based in Washington, D.C., conducted a pilot this year with the Lance Armstrong Foundation in five of its centers called Live Well! Life Beyond Cancer, a six-week community-based program that provides education and support programs. Ms. Thiboldeaux says preliminary findings from a study of the program show that participants reported significant increases in their physical and social functioning roles, and there was a significant decrease in health-related worry. The program will be expanded to 10 other sites in early 2008 with the aim of making it available at other centers across the country and at local hospitals and cancer centers.

Some recent studies have debunked the notion that state of mind plays a role in cancer survival. Last month, a study in the journal *Cancer* found that over a 10-year period, neither a positive nor negative emotional state had any effect on cancer survival or the progression of the disease in head and neck cancer patients.

But that doesn't negate the importance of paying heed to quality-of-life issues, or the need for psychosocial services such as therapy and support groups, says the study's lead author, James C. Coyne, director of the Behavioral Oncology Program at the University Of Pennsylvania School of Medicine: "Sometimes people just need a connection and a community where they can validate their experience."