your health > QUALITY OF LIFE

BY JENNIFER L.W. FINK, RN

CARE for the whole person

No matter your cancer experience, palliative medicine comforts body, mind and soul.

MY 57-YEAR-OLD MOTHER COULDN'T WAIT TO HAVE THE CANCER REMOVED from her breast. Like most anyone who is diagnosed, my mom naturally focused only on the tumor itself. But cancer, we soon learned, is more than a mass of malignant cells. My mom's experience caused her to question her faith, left her with lingering pain and limited her ability to enjoy her hobbies, even years after treatment had eliminated the cancer.

Increasingly, researchers and clinicians are recognizing the benefits of using palliative care to address the physical, psychological, spiritual and social concerns that patients and caregivers may face—and they're taking a cue from hospice care.

"Over the last decade, people have begun to look at how we can implement all the great things that happen in hospice—attention to symptoms, psychological support, family support, spiritual support—from the time of diagnosis," says Betty Ferrell, RN, PhD, a research scientist with City of Hope Cancer Center in Duarte, California. "Palliative care is about enhancing quality of life throughout the disease trajectory."

But misconceptions about palliative care abound. "The biggest misconception about palliative care is that it should be reserved until the final weeks of life," says Ferrell, a three-time American Cancer Society grant recipient and the 2010 winner of the Society's Irish Green Quality of Life Research Award. "The reality is the complete opposite. Palliative care should be implemented at the time of diagnosis."

Changing perspectives

Today, patients and families should expect symptom management as part of their cancer treatment, enabling them to avoid being excessively burdened by the disease or its treatment side effects. Integrating palliative care may include counseling and/or medication to deal with cancer-related depression, a pain-control regimen to enhance mobility and energy, or assistance with care coordination to ensure that the treatment plan matches the needs of the patient and the family.

A pioneer in the field of palliative medicine, Ferrell is pleased to see this specialized care being used more widely to improve patients' lives. "When I started in oncology 34 years ago, we didn't know how to manage nausea," she says. "We knew nothing about fatigue. We were limited in our knowledge of pain management. Now, we have ways to support people throughout treatment. Nausea and pain, for instance, can now be effectively treated."

In part, these advances are the result of research sponsored by the Society, along with the National Palliative Care Research Center. Since 2007, this collaboration has funded 64 related research projects worth $9 million, with 14 new grant recipients added this year. The Society's commitment to quality-of-life research addresses a lack of federal funding and nurtures a pool of new scientists. As a complement, the American Cancer Society Cancer Action Network (ACS CAN), the Society's advocacy affiliate, is focused on making quality of life a legislative priority. Because of these collaborative efforts, the Society was recognized earlier this year with a Presidential Citation awarded from the American Academy of Hospice and Palliative Medicine.

Changing minds

While the number of palliative care teams in hospitals is growing, too few people in need realize that this specialized care is available. "Patients and families simply don't know what they don't know," says Rebecca Kirch, the Society's director of quality of life and survivorship.

Moreover, some care professionals still shy away from quality-of-life discussions. In 2010, ACS CAN surveyed 1,000 adults with cancer or a history of cancer, with questions focused on quality of life. Fewer than one-third reported being asked by their doctors about quality-of-life concerns during or after treatment. Only 43% of respondents reported any discussions with their doctors about pain relief, and just 47% of those experiencing cancer-related stress, depression or anxiety actually received information, care or a treatment referral to help address their emotional needs.

"Quality of life should be a part of every encounter that patients and survivors have with the health care system," says Kirch. "The Society is in a unique position to help everyone—patients, caregivers and physicians—understand why palliative care is a lifelong to experiencing improved quality of life and survivorship."

talking points

Discuss these important quality-of-life issues with your doctor or nurse. For additional support services or information about pain management and palliative care, contact your American Cancer Society at 1-800-227-2345 or visit cancer.org.

PAIN CONTROL: Don't assume that cancer-related pain is part of the game. Effective pain relief treatments, ranging from nonmedical interventions such as massage and electrical stimulation of pain pathways to prescription medications, are available.

NUTRITION: Cancer can steal your appetite: physical symptoms such as mouth sores and nausea make eating painful and unappealing. Your physician can help alleviate your symptoms and refer you to a registered dietitian for help in planning healthy, more easily tolerated meals.

DEPRESSION: According to the National Cancer Institute, 15 to 25 percent of cancer patients also experience clinical depression—which may cloud judgment, cause distress, impair functioning or even lead some individuals to not follow through with their treatment plan.

Tell your physician about any cancer-related emotional concerns and ask for a referral to specialized psychosocial care so you can feel better.

SPIRITUALITY: If anything will cause you to question the meaning of your existence, it's cancer. It's OK to let your care team know that you're struggling.

FAMILY SUPPORT: Cancer affects the entire family. Support groups and/or counseling can help everyone cope.

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