

FEATURE STORY

# The New Specialty in Cancer Care

BY JOANNE KENEN

*Palliative care is catching on in centers across the country, improving quality of life for patients along the way.*

On November 11, 2000, Mark Quasius, then 37, learned that the strange sensation in his right ear was caused by a rare carcinoma in his upper sinuses.

After a variety of treatments, including multiple surgeries on his head, lungs, pancreas, and hip bones, the prognosis for his advanced adenoid cystic carcinoma is pretty good. After consultation with Andrew Putnam, MD, a palliative care specialist at Lombardi Cancer Center and Georgetown University Hospital, his life is pretty good too. Dr. Putnam brought Quasius's unrelenting pain from the tumor behind his right eye under control after surgeons concluded that, for now, the risk of removing the tumor outweighed the benefits.

Quasius, now 44, can't work at his old engineering job anymore. But he can still stroll down to the pond on his 30-acre farm south of Washington, D.C., still keep himself engaged with fun fix-up projects around his home, and still appreciate every day he has "with my wonderful, wonderful wife, Beth."

That people are living longer with cancer as a chronic disease is well known. Because of the growing field of palliative care, people, like Quasius, are also living better.

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A desperate need to find relief from pain prompted Mark Quasius, shown with his wife, Beth, to see a palliative care specialist. Photo by Sara Lewkowicz

Palliative care was once a scary word for hospice. Palliative care, the art of easing physical, emotional, or spiritual distress arising from a serious illness, is still the core of hospice care but it now takes place in many other settings—hospitals, nursing homes, and, now increasingly, in outpatient cancer clinics.

Unlike hospice, palliative care patients don't have to have a life expectancy of six months or less. They don't even have to be dying. And they don't have to give up radiation, chemotherapy, or surgery in order to get “comfort care.” Doctors sometimes refer to palliative care as “concurrent care” or “a continuum of care” that can start early in treatment, sometimes even right at diagnosis. The idea is to give patients what they need when they need it, no matter what their ultimate prognosis.

That means both sophisticated medical management of symptoms, such as pain and fatigue, as well as enhanced communication about patient choices. This concept fits the biological principle that illness doesn't turn from a treatable to terminal situation overnight, but may do so gradually, or even drift back and forth.

“When we walk in, it doesn't mean we're not going to treat your cancer anymore. It means that here is someone who is going to focus on the quality of your life, who is going to focus on other aspects of living beside the disease,” says Dr. Putnam. “The oncologist will focus on what the oncologists do best—and want to do. But you'll also have someone who is going to concentrate and focus on the quality of life.”

Research is now providing the hard data to show the intervention works. A growing number of studies have reported benefit in quality of life for patients receiving palliative care. A recent study conducted by nurse-researcher Betty Ferrell, PhD, RN, and her colleagues at City of Hope in California found a better quality of life and fewer management barriers related to pain and fatigue among lung cancer patients receiving palliative care compared with those who did not receive the intervention.

## Getting Access

When Heather Thomas, 34, of Vermont, fell on her kitchen floor a year ago, breaking eight vertebrae and three ribs, her doctors “wondered why I had bones that looked like an 80-year-old woman who never drank milk,” she says. The reason was metastatic breast cancer in her liver and bones. She knows her cancer won’t be cured, but it can be treated. Palliative care at Dartmouth-Hitchcock Medical Center in Lebanon, New Hampshire, is helping her keep her strength, her spirits, and her sanity.

“If something comes up that I don’t understand or I don’t know who to talk to, their only goal in life is to find the answer. It’s like trying to learn a whole other language when you get a cancer diagnosis. They are my translators,” Thomas says.

Some hospices, particularly larger ones, are developing community-based palliative care programs for cancer patients outside the traditional hospice model, either because death is not imminent or because they are not emotionally ready for hospice care. But they still have pain, symptoms, and emotional issues, and a palliative care team can fill the gap, smoothing the transition to hospice in those cases where it is eventually appropriate.

Some hospices have introduced an approach called “open access,” meaning the patient does fit the standard definition of a hospice patient, including the six-month prognosis, but doesn’t necessarily have to give up treatment, at least not immediately. Though some insurance companies, including Aetna and UnitedHealth, cover open access, it isn’t available everywhere, and it isn’t offered to every patient who may want it. But for some it is a gentle bridge over a chasm between aggressive curative care and what may feel like giving up.

Open access has struck a chord,” says Carolyn Cassin, head of Continuum Hospice Care, a nonprofit in New York that offers it. “Everyone at the end of life has a right to specialized care, just like you are entitled to emergency room care if you are hit by a bus. The old-fashioned hospices defined themselves by what you could not have. They had relegated themselves to brink-of-death care. But if it’s only brink-of-death care, it’s not that useful. Open access provides a transition. That’s our core business—transition.”

Not every patient who needs palliative care gets it. Not every hospital offers it because of limited resources, and referral can come late. “There is still a mentality of cure, cut, and fix,” says Ferrell, who has been a national leader in training nurses in palliative medicine. “Too often we look at, say, the cancerous lung and forget about the rest of the person.”

Yet it’s changing. At the major cancer centers around the country, from City of Hope to Memorial Sloan-Kettering Cancer Center in New York, palliative care has become a component of cancer care for inpatients and outpatients, and insurance plans generally cover it. Some programs are more ambitious and far-reaching than others. But almost always the oncologist remains the primary doctor, with the palliative care team consulting just like any other medical specialist.

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palliative care was for either option. ”

—Patty Szostak

“When they asked me if I would be interested in seeing people from the palliative care unit, I didn’t know what to say,” recalls Patty Szostak, 53, who is being treated for a recurrence of non-Hodgkin’s lymphoma at Dartmouth-Hitchcock. “Is this a death sentence? Are you telling me I’m terminal?” But once she understood palliative care, it made all the difference, not just in her physical comfort but in her emotional and spiritual health. The Dartmouth-Hitchcock team managed her physical symptoms, but also made sure Szostak, an artist and writer who meditates, does yoga, and tends to her horses in Vermont, got massages, Reiki, and even a serenade from a harpist.

Szostak’s response to treatment has been uneven; at one point she was very ill with the cancer infiltrating her brain. “There were two paths I could travel, a path to physical healing or another path that could lead to my death. And somewhere along the line, I realized palliative care was for either option.”

### Pain as the Starting Point

Pain is usually what gets the patient to the palliative care team; that’s what initially brought Quasius to Dr. Putnam. But once patients walk through the door, palliative specialists often find other physical symptoms, such as severe fatigue, that the patient may have wrongly assumed were inevitable aspects of life with cancer. The specialist may also address the complicated family dynamics that can burden a cancer patient, or, sometimes, the rough decisions about how aggressively to pursue treatment.

“What palliative care does first of all is improve how you feel,” says Susan Lowell Butler, 64, a 10-year survivor of simultaneous breast and ovarian cancers who endured an arduous clinical trial and is now executive director of the DC Cancer Consortium advocacy group. “You tend to feel that everything you feel is a side effect of the cancer rather than of the treatment, when in fact most of those symptoms are perfectly manageable for most people. With palliative care you don’t have to fight the side effects, so you can just fight the cancer.”

Not every cancer patient will need to call in the palliative care cavalry; some cancers are easier to treat than others. “We get the more complicated constellations of physical symptoms, psychosocial, and spiritual needs,” says Janet Abrahm, MD, a palliative care physician who treats outpatients at Dana-Farber Cancer Institute and inpatients at Brigham and Women’s Hospital in Boston. “The [oncologist] has done the best he can but the person is suffering. Then they call us.”

Palliative medicine was recognized officially as a medical subspecialty in 2006 by the American Board of Medical Specialties, with growing training opportunities for physicians and nurses. Much of it involves administering state-of-the-art pain medication. Some clinics are using high-tech approaches, including various types

of nerve blocks or pain pumps. But they also treat symptoms that cancer patients are all too familiar with, including neuropathy, fatigue, nausea, constipation, mouth sores, shortness of breath, and anxiety.

“We have more weapons in our armament for symptoms than the oncologist does,” says Dr. Putnam.

The palliative care team, which can involve doctors, nurses, social workers, chaplains, physical therapists, and nutritionists, can intervene in a crisis. But often palliative care can avert a crisis and let the patient avoid hospitalization and frantic trips to the emergency room, says Nessa Coyle, RN, a national leader in palliative care nursing at Sloan-Kettering. Some patients will only need palliative care during rigorous treatment; others will need ongoing assistance.

Laura Massey, 55, endured just about every side effect imaginable both before and after a stem cell transplant for chronic lymphocytic leukemia. Now in remission, she receives ongoing palliative care at Moores Cancer Center in San Diego for a host of symptoms, including chronic pain, fungal infections, and muscle weakness. She can play with her new grandson, and wants to learn to sail.

“I wouldn’t be here without the support of a million people,” she says gratefully.

## Family Communication

Physical pain is not the only aspect of cancer pain; psychological and spiritual pain also take a toll. Family dynamics can become painfully snarled. Values can clash as families grapple with tough decisions about treatment. Palliative care can help here too.

Addressing emotional issues is a priority at Moores Cancer Center, where the palliative care team falls under a larger “science of caring” umbrella. All patients are assessed at the outset; certain emotional red flags trigger a palliative care consult, sometimes even if the physical prognosis is fairly good, says Kathryn Thornberry, LCSW, a social worker who is part of the Moores palliative care team.

“You’ve got to assess cultural, emotional, and psychological issues, as well as values,” says Thornberry, who has worked with families of various ethnicities and religious beliefs as they set goals of care. “You have to help the family understand that it’s the patient’s decision. Sometimes they think the whole family gets to vote.”

Moores is a trailblazer in creating the continuum. Like many of the top cancer centers, patients can go back and forth as needed between the Moores outpatient clinic and the adjacent teaching hospital. But Moores has an unusually close relationship with San Diego Hospice. Some doctors work in both settings, treating patients who need support while they fight their cancer, as well as helping patients with a grimmer prognosis transition to hospice.

Usually the palliative care team leaves decisions about treating the disease to oncologists since they know more about the specific patient’s disease and available therapies, says Neal Slatkin, MD, director of palliative medicine at City of Hope. But, he says, sometimes the palliative team has a perspective the oncologist

may lack, and can work with oncologists to review goals of care and take another look at what outcomes are realistic to expect. No one ever tells the patient what to do, but they make sure the communication is clear and patients know what's going on. "It can be very hard for the oncologist who has been treating the patient for years to stop. They care too," says Sloan-Kettering's Coyle.

When she was preparing for a stem cell transplant, Patty Szostak felt that concern from the oncologists and the palliative care team at Dartmouth-Hitchcock. "I get scared. I do get scared," she confesses. "But I am able to feel joy. And I still have a mental image of myself at age 90 in my garden with the cats running around, and me pressing seeds into the ground. That's the picture I have. And I'm not giving up on it."