Cancer Health™

The New Palliative Care

This team-based approach can ease symptoms and improve quality of life for anyone living with cancer at any stage.

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For Iris Vander Pluym, 53, a New York City writer and musician who was diagnosed with Stage III colorectal adenocarcinoma in the late summer of 2017, the really bad stuff happened afterward. “I no longer had cancer, but the treatments have been a lot crueler than the disease ever was,” she says.

Treatment started that fall. Pluym (a pseudonym to protect her privacy) had two four-week rounds of chemotherapy followed by 28 rounds of radiation therapy. In early 2018, after the tumor had shrunk, she had surgery, which entailed a temporary ileostomy (an opening in the abdomen where stool is redirected) to let her colon heal. Infections landed her back in the hospital twice. In May 2018, she started more chemo, which left her so weak she couldn’t lift her arms to shampoo her hair. By July, her surgeon reversed the ileostomy. Scans showed no cancer.

But by September, her pain was increasingly unbearable. Late radiation effects caused significant portions of her formerly healthy intestines, cervix and vagina to deteriorate. She had recurrent urinary tract infections and urinary and bowel incontinence. Hyperbaric chamber therapy (breathing pure oxygen in a pressurized room) helped with the pain somewhat but also caused capillaries in her eyes to burst, which required laser treatments and painful injections. “For those keeping score at home,” she wrote in her pseudonymous blog, “Yes, we are now treating the side effects of treatment for side effects of treatment for cancer.”

By December 2018, when she saw an ob-gyn oncologist about repairing her vaginal and cervical tissue, she was referred for a new kind of help. In January 2019, she blogged, “I get myself a palliative care specialist. OMG you guys! Everyone should go get one right now!”

What Is Palliative Care?

Sometimes called supportive or comfort care, palliative care is specialized team-based medical care for people living with a serious illness. The focus is on improving quality of life at any stage of disease. In cancer care, it can help people whose treatments may cure them, people whose treatment is designed to manage their cancer as a chronic illness and people who are facing the end of life.

A modern palliative care team typically includes four experts: a physician, a nurse practitioner, a social worker and a chaplain. These individuals work hand in glove with the oncology team to help manage symptoms (pain, fatigue, nausea, weight loss, breathing problems), psychological issues (anxiety, depression), practical issues (transportation, finances) and spiritual concerns (grief, bereavement).

“We are good at symptom management, communication and care coordination,” says R. Sean Morrison, MD, who founded the palliative care program at Mount Sinai Health System in New York City, where Pluym was treated. In 1997, it was one of five in the United States, but “now every academic medical center in the country has one. We help match treatments to patient goals and coordinate care in a very fragmented health care system.” Morrison is also director of the National Palliative Care Research Center.

Even now, however, most people don’t understand palliative care—even professionals who care for people with cancer. “Doctors, nurses, clinicians, most say they know what it is, but they are wrong—they equate it with hospice or end-of-life care,” Morrison says. While palliative care did originate with the hospice movement in the late ’60s, it has evolved. “We’ve transformed some cancers, such as ovarian cancer, into chronic illnesses people live with, but that means that they are experiencing not only the distress caused by the disease but also by the treatments.” That association with end-of-life care means some people are scared to meet with palliative care specialists, says Mount Sinai Health System president David Reich, MD. Instead, he says, “You should be delighted. These are amazing, empathic people. They will make your life better.”

If your cancer treatment is simple and curative and side effects are minimal, you probably won’t need palliative care. But it’s an important option for anyone who experiences or can expect one or more distressing symptoms, including those undergoing intensive treatments such as stem-cell transplant, treatment for head and neck cancer or “anyone facing an uncertain prognosis,” says Morrison. Private insurance, as well as Medicaid and Medicare, may cover many of the clinical services involved in palliative care.

The best time to start? Right after diagnosis. Research has found that providing patient-centric palliative care early in treatment improves outcomes, often as effectively as the latest drug. In a landmark 2010 study published in The New England Journal of Medicine, patients with metastatic non-small-cell lung cancer who received palliative care lived an average of 11.6 months versus 8.9 months—even though they opted for less aggressive treatment. Subsequent studies have confirmed those benefits.

Easing burdens of pain, fatigue, depressive symptoms, sleep problems and worry often gives people the strength they need to carry on with their cancer therapies. Says Morrison, “When we provide palliative care at the onset of cancer care, people feel better, are more likely to complete treatment and live longer, and they and their family experience a better quality of life.”

Stretcher to Wheelchair to Walking

Radiation oncologist Kavita Dharmarajan, MD, who in 2013 started one of the first palliative radiation centers in the country at Mount Sinai, remembers getting a call about a woman in her

50s who had metastatic stomach cancer with lesions in her liver and lungs and a blockage in her stomach. The bedridden woman couldn’t eat, was constantly vomiting and had lost 50 pounds. She was too sick for more chemotherapy or discharge yet refused hospice.

Dharmarajan gave her a five-day course of radiation. That was enough to clear the blockage while adding little or no extra symptom burden. The woman was discharged to a rehab center. A month later, she came back for her follow-up visit. She was brought in on a stretcher, but her mass had shrunk, her appetite had improved and she felt better. She started chemo again. Three months later, she returned—in a wheelchair. Three months after that, when she came back again, she was taking two chemo agents and walked in. “She survived at least two years longer than her prognosis, which had been weeks,” says Dharmarajan.

Radiation is a double-edged sword. It is remarkably effective for pain relief, especially for bone metastasis, significantly easing pain more than half the time. But it can have serious side effects, including fatigue and skin burns. To develop a palliative plan, Dharmarajan works closely with the patient, family and the oncology team to elicit treatment goals and preferences.

Larger doses of radiation may shrink a tumor more but leave the patient in distress. When a cure isn’t possible, “lower doses may not completely eradicate the tumor but can shrink it enough to relieve pain,” she says. “My mindset is to give what I need to without hurting the person.”

Walk, Don’t Run

“Quality of life may mean doing very simple things with your loved ones,” says Mount Sinai geriatrician and palliative care expert Bethann Scarborough, MD. For cancer-related fatigue, she’ll address medical issues (blood count, thyroid levels), prescribe medications (steroids, stimulants), help with sleep issues and work to reframe expectations. “The goal may be to help you harness your energy so you can clean the house or walk your dog.”

She recalls one man in his 50s with multiple myeloma. He’d been a competitive runner. Now, he was so fatigued that he gave up on exercise entirely, which depressed him deeply. She gently asked him to try walking a mile in the morning. He did, and it felt good. Then he started walking a mile in the evening too. That felt even better.

At its core, palliative care is about helping people clarify what is most important to them and use that self-knowledge to achieve what they really want. “Our role is to provide a safe and neutral space where you can ask questions, become informed and get the treatment to achieve the goals you want,” says Scarborough. Palliative care can help people choose how they want to live—and, if it comes to that, how they want to die.

Difficult Decisions

“Great palliative care means learning from people what their goals are, because people have priorities for life besides just survival,” Atul Gawande, MD, author of Being Mortal, told the audience at the 2019 American Society of Clinical Oncology annual meeting. “Our core mission is to enable their goals—health, family, financial—and recommend to them what, from our experience, gives them the best possibility of achieving those goals."

Clinicians can help patients clarify their goals with a few simple questions, he said. What are your goals for quality of life? What matters to you most? What, exactly, does that mean in your everyday life? Where will you draw the line at what you will accept? He described one patient who had a simple, concrete criterion. "He told me, 'If I can eat chocolate ice cream and watch football on television, keep going. If I can't, let me go.'" That, said Gawande, "is the best living will I have ever heard."

When treatment options narrow, or disappear entirely, addressing the emotional impact is essential, says Mount Sinai medical oncologist and palliative care physician Cardinale Smith, MD, PhD. She'll acknowledge how difficult it may feel to learn that there are no more available options. Opening up that emotional discussion can lead patients to identify very personal goals.

"I may ask, 'Now, with whatever time you have, what do you want to achieve?'" she says. "Treatment options can help meet those goals." Some people are willing to go through the toxicity even for an extra week of life, while others value quality over quantity. "If we don't invite the discussion, we won't know what is right for you," says Smith.

Making Music Again

By the time Pluym went to see her palliative care physician, she was bedridden, leaving the house only for appointments and treatments. Her new palliative care doctor consulted with her oncologist and gynecologist and performed physical, emotional and neurological exams. Pain relief was paramount. "I'd be having an ordinary good day, but then physical pain would throw me into an emotional tailspin," recalls Pluym.

Her new doctor told her, "We've got to get you some pain relief.'" Pluym's oncologist had prescribed morphine and other opioid painkillers, but in low amounts that her palliative care doctor referred to as "little old lady" doses. "My oncologist didn't want to go higher, and I didn't want to get addicted," recalls Pluym.

Her palliative care doctor switched her to just morphine, doubling the dose and increasing the frequency to every eight hours from every 12. "When that didn't work, she doubled it again," recalls Pluym. She also prescribed gabapentin, a nonnarcotic pain reliever, and went to bat with the insurance company and the pharmacy to get approvals. "She told me, 'When we are talking about pain for a cancer patient, we take the gloves off.'"

By the end of March 2019, Pluym's pain wound down. Her palliative care doctor weaned her off the drugs safely. "I don't take any pain medications at all now, not even Advil."

That spring, she bought a new keyboard and started playing at her neighborhood bar. She took the summer of 2019 off from treatment and traveled to see friends in Knoxville, Tennessee, and Duluth, Minnesota. In November, she had major reconstructive surgery and once again benefited from palliative care for temporary pain relief. She still gets tired and may need a long nap after, say, doing laundry. “These normalcies that are taken from you—they may seem insignificant, but they are huge,” she says. “I’ve gotten little pieces of my life back.”

Her only regret is that she wasn’t introduced to palliative care earlier. “I would have liked to have known my palliative care doc when I was getting radiation and started to have pain,” she says. “She’s an ally. She was the

last link in my chain, but I wish she had been one of the first.”

Palliative Care Resources

The Center to Advance Palliative Care runs a website (GetPalliativeCare.org) that provides educational resources, including patient handouts, checklists, webinars, videos and personal stories. It also has a national palliative care provider directory that can be searched by ZIP code. For advance care planning, which helps individuals identify preferences for treatment if they become incapacitated, useful sites include Five Wishes (FiveWishes.org) and Prepare for Your Care (PrepareForYourCare.org).
