In a landmark study published in 2009, Marie Bakitas, D.N.Sc., an associate professor of anesthesiology, found that palliative care offers significant benefits to patients with advanced cancer. Patients who received palliative care as part of the trial—called ENABLE II, for Educate, Nurture, Advise, Before Life Ends—had a higher quality of life and better mood than patients not enrolled in the palliative care program. In a follow-up to the study, oncologists who had participated praised the benefits palliative care brought to their patients. And in 2012, the trial was one of seven studies cited by the American Society of Clinical Oncology in support of its conclusion that palliative care should be an option for patients with metastatic cancer. Still, the 2009 study left several questions unanswered.

“While we know that palliative care is effective, we don’t know specifically what works,” says Bakitas. “We currently have a follow-up study to identify the mechanisms at work and the characteristics of the people who benefit the most.”

Bakitas and her team will also look at family caregivers. In ENABLE II, while patients who received palliative care saw improved quality of life, their caregivers did not.

“We hadn’t designed the protocol specifically for caregivers,” Bakitas explains. “In our current study, we’re testing a parallel intervention for caregivers to take part at the same time as the patients. They’ll receive their own separate coaching sessions and materials.”

As a further step, Bakitas has joined forces with Alan Kono, M.D., an assistant professor of medicine and a cardiologist at Dartmouth-Hitchcock, in a pilot study funded by a Dartmouth SYNERGY translational research grant. The study will provide palliative care to patients with heart failure. Ten patients, and their caregivers, will participate in the intervention. The participants will advise the study team by reviewing the materials and providing feedback, which will allow the team to refine the materials before enrolling a larger group of patients and caregivers.

Many patients with heart failure have prognoses similar to those for advanced cancer yet do not see themselves in a similar light. Helping them appreciate how palliative care can benefit them requires a deft touch.

In a recent face-to-face consultation, Bakitas asked a patient with heart failure what the patient knew about palliative care.

The patient replied, “If you’d asked me a couple of months ago, I’d have said palliative care means ‘hospice,’ and ‘you’re dying.’” But the patient learned from talking to Kono that “it’s about quality of life, dealing with symptoms, and supporting me and my family when we have to make some difficult health-care decisions.”

Kono points out that heart disease causes even more deaths than cancer does. “We’ve seen that palliative care increases quality of life when it’s introduced early in advanced cancer care,” he says. “We’re hoping a similar approach will offer the same benefits to patients with heart failure and allow them to make shared decisions they’re more comfortable with. Why spend a year in the hospital when you can spend it at home?”

While these new studies show promise for patients and caregivers, educating clinicians is an equally important goal. Fortunately, a new grant from the Health Resources and Services Administration will allow Bakitas and her colleagues to offer low-cost educational seminars to all levels of nurses—from faculty to practicing nurses to nursing aids—across rural northern New England. And she’s considering additional studies on palliative care in more urban and diverse populations than those in the Upper Valley.

“Palliative care is not about dying. Our approach is about helping people live better every single day,” says Bakitas, emphasizing each word. “It’s about living.”

Susan Warner