When the end of life begins is not a place of clear delineation, where lines are painted on the road to guide the way. Cancer, in particular, can be more like a meandering stream, its course turning this way and that, first rushing then slowing, changing with the effects of treatment.

This uncertain, complex path calls for flexible care that addresses more than seeking a cure. The symptom control and palliative care program at M.D. Anderson Cancer Center is incorporating palliative care earlier in the disease process and alongside curative care. Patients who are still seeking a cure for their cancer can experience pain, nausea, confusion, shortness of breath, and emotional distress, all of which can be addressed. “As the disease process progresses and curative treatment is not effective, palliative care can help in the transition from the active treatment to hospice care,” explains Ahmed Elsayem, M.D., medical director of the program’s 12-bed palliative care inpatient unit.

The inpatient unit allows staff to focus intently on symptom control for patients with complex, severe symptoms. “The patients who typically need us aren’t going directly to hospice,” says Patti Knight, patient care nurse manager for the unit. “We get people who really are struggling with what the right decision is.”

The palliative care unit has diverted patients from the ICU, allowing those who die in the hospital a more comfortable end of life. The number of deaths in the ICU dropped significantly since the opening of the acute palliative care unit. Nineteen percent of hospital deaths now occur on the palliative care unit. “For people who are going to die in the hospital, that’s a better death,” Elsayem says.

Having the unit, which opened in January 2002, also makes things easier for nurses, who in a scattered-bed model might have to care one moment for a patient being treated aggressively for cancer and the next for one who is quite sick and facing death. “Here we have nurses who have chosen this as a career path,” says Eduardo Bruera, M.D., chairman of the department of symptom control and palliative care. “Not every nurse feels comfortable or confident to deliver care to these very ill patients.”

Patients throughout the cancer center can receive supportive care from a palliative care team. The team travels to any department to offer “just in time” relief of physical and psychosocial suffering. Despite initial doubts, physicians began calling in the team for patients with difficult or complex pain, nausea, or emotional distress.

The palliative care program has quickly gained support within the hospital. In 1999, the service’s first year, eight percent of patients who died at M.D. Anderson received palliative treatment; that went up to 54 percent last year. “A small number of physician leaders started using us,” recalls Bruera. “Fortunately these staff doctors were credible people. They said, ‘My life is easier since I used these people.’ That started the process of people talking to each other and starting to try us.”

The palliative care team offers to work with colleagues in the way that best suits the physician. “They can use us as a sounding board for problems, maybe once or twice as consultants,” Bruera says. “Or second, we can work on a parallel ongoing basis, working with the patient and family. Or the third model, in which the oncologist believes care can be transferred to us. We tell them, ‘We will work with you in whatever way you feel most comfortable.’” Importantly, he adds, the palliative care team must “respect the ongoing relationship between a primary doctor and the patient.”
Furthering palliative care as a profession is also a major goal at M.D. Anderson. The program will host four palliative care medical fellows next year in a program that is one of the first in the country to be accredited. Oncology fellows at M.D. Anderson will have a month-long rotation in palliative care starting this fall.

In a unique program called “bus rounds,” groups of cancer center physicians board a bus to visit patients at their homes in rural parts of Texas and consult with local hospices. This is part of the program’s outreach effort to local hospices, which has resulted in raising the level of end-of-life care throughout the Houston area. “Each side learns from the other side; it creates relationships,” explains Kay Swint, RN, clinical administrative director of the symptom control and palliative care program. “That has been a really winning program. We get more requests to do bus rounds than we can handle.” In one case, a physician from M.D. Anderson met a like-minded hospice nurse. The pair ended up developing an ongoing collaboration that has resulted in shared conference presentations and publications.

Armed with a faculty member holding a PhD in biostatistics, the palliative care program generates an impressive amount of original research, publishing more than 200 papers since 1999 in both palliative care and oncology journals. The program’s physicians have also published their own handbook on symptom control and palliative care, covering everything from pain assessment to giving bad news.

Patient care includes music and massage therapy for inpatients. A specially designed outpatient center has no waiting room; instead patients and their families are ushered immediately to a room with a bed, comfortable chairs, and a private bathroom. Another successful idea has been the weekly family tea, which allows patients, family, and staff to get to know one another in a less formal atmosphere.

Palliative care as it is being redefined and expanded at M.D. Anderson includes these and many other specialized services for people facing life-threatening illness and death and their families. Almost as important as the care itself is the program’s mission to educate other health care professionals in this new way of thinking about what people and their loved ones need at the end of life. “There’s been this feeling that near the end of life, you step down care,” says Bruera. “What I’ve seen is that you really need to step up care.” •