Even clearest dying wish can get muddied

Tensions arise when families, doctors fail to communicate

BY JEREMY OLSON
Pioneer Press

Dr. Ron Cranford was one of the nation's top right-to-die advocates, providing influential opinions on vegetative patients such as Terri Schiavo and creating the "DNR" order that allows patients to refuse resuscitation.

When diagnosed with kidney cancer in 2003, Cranford made his wishes clear: He didn't want any long-shot treatments and he wanted to die free of pain. Married to a former Hospice social worker, Cranford felt he had the advocate he needed as well.

And yet when the moment came this May to choose whether to control his pain or prolong his life, there was tension and disagreement and doubt.

"Ron was the champion of humane treatment in end-of-life situations," Candy Cranford said. "I was his advocate, and I'm a strong advocate. And yet the two of us had a hell of a time getting to where we needed to get."

Decisions about the end of life are never easy, growing more complicated as medical research has invented more ways to prolong life. Communication problems make decisions tougher than necessary. Sometimes, families are uninformed. Sometimes, doctors lack the training or will to confront death. The result, at worst, can be relatives shouting at one another over what to do, doctors refusing family demands for unnecessary treatment or patients undergoing questionable procedures because nobody offered better alternatives.

Hospitals are responding to such problems by hiring third parties that are trained in mediating disputes or in providing comfort and pain relief — known as palliative care. Medical schools are increasing training on end-of-life care as well.

The key is getting doctors to talk with patients and to recommend palliative care at the right time, said Dr. Diane Meier, who directs the Center to Advance Palliative Care in New York.

Meier's medical career changed a decade ago after confronting a dying cancer patient whose legs and arms were restrained because he kept pulling a life-saving feeding tube from his nose. The patient couldn't communicate, so Meier asked his doctor — an intern — why the man was restrained and why his feeding tube was put back 30 times.

"He looked at me with so much distress and pain in his eyes and said to me, 'cuz if we don't do that, he'll die,'" Meier said. "Clearly, not only did this intern not understand what good care for the dying was — that this patient was dying no matter what he did — his chief resident didn't know, his fellow didn't know and his attending didn't know. All these doctors wanted to do the best they could for this patient, but they didn't know how."

Cranford, 65, felt intolerable pain shortly after he was admitted to Hennepin County Medical Center on May
Even clearest dying wish can get muddied

22. The quandary was that his pain wasn't directly caused by the cancer, but by a blood clot.

The pain and recurring back spasms intensified by the third day in the hospital. Cranford told his wife that he wanted higher doses of pain medication even if it threatened his survival. He had lived more than two years with cancer, traveling extensively with his wife and continuing his work, and now felt comfortable letting go.

Cranford's wife brought that plan to the doctors, and they agreed to strengthen the pain medication. But they convinced her that they should continue trying to treat the clot. She agreed but knew her husband would be frustrated by the diversion from his goals and would need support.

"How are you going to treat his emotional pain?" she asked the resident in charge of Cranford's care.

"I don't know what you mean," the doctor replied.

After trying several drugs, Cranford felt the focus still wasn't on controlling his pain but on pursuing treatment. His patience ran out after one full week in the hospital.

"How did we get here?" Cranford asked his wife. "No one has listened. I feel like everybody has abandoned me."

"This," his wife replied, "is the last night you'll ever have to be in pain."

She called a hospice center in Edina and reserved a bed.

Unlike the Cranfords, most families don't talk about death. A new survey suggests elderly parents and adult children want to talk but are waiting for one another to start.

Doctors don't bring it up, because they don't want to imply that they are giving up or expose themselves to lawsuits. They tend to focus on diseases, not people, and talk in medical jargon that confuses patients and prevents families from thinking about their wishes, said Dr. Steven Miles, a bioethicist at the University of Minnesota.

Families are "not only poorly equipped to make the decisions, they're often surprised by them," Miles said. That's when the fights can start.

And that's when the hospital ethics consultants are called in. They resolve power struggles among adult children who don't know whether their parents want artificial life support. They calm doctors who are ready to transfer patients whose relatives demand care that offers high risk and little benefit.

"A lot of times it's just a lot of miscommunication, misunderstanding, false hope," said Dr. Howard Epstein, medical director of palliative care at Regions Hospital in St. Paul.

Sometimes, it's doctors who want to keep fighting. Doctors tried to persuade Candy Cranford to keep her husband at the hospital, but she refused. They then helped prepare Ron Cranford for the move to hospice on May 30.

Cranford's grown children were there, and he enjoyed a brief visit from his beloved dog, Sole. He died shortly after 3 the next morning while holding his daughters' hands.

Even in grief, Cranford's wife was relieved she could help her husband die as he wished. It frustrated her, though, that the doctors were able to attend to her husband's physical pain but seemed confused when she
sought care for his emotional and psychological pain.

Candy Cranford is working with leaders at HCMC to form a palliative care team. She holds no grudges. The doctors were only following their training and experience and doing what they thought was best for what appeared to be a treatable condition.

If she wondered whether she should have fought harder to keep her husband alive, her answer came in a computer file she discovered. Dated Jan. 1, 2006, it was a draft by Ron Cranford titled "My Personal Journey with Cancer."

I want to be remembered for how I lived, not how I died during the last few minutes, hours, or days. In the final trajectory of dying, when I am no longer me, I want to be kept as comfortable and pain free as possible, and if necessary unconscious with appropriate sedation. I want my loved ones to remember me for my living, and my days of living with cancer, not dying from it when the disease overwhelms the person.

Maybe once a month, Candy Cranford replays a family DVD just to hear her husband's voice. She misses her soul mate, but has some peace.

"If we wouldn't have gotten out of the hospital," she said, "I would have spent the rest of my life wondering, 'How did I fail him?' "

Jeremy Olson can be reached at jolson@pioneerpress.com or 651-228-5583.