Nancy Yedlin’s father had been active, “full of life” until fast-moving brain cancer struck him just before he turned 81.

He had an advanced directive that would limit aggressive treatment at the end of his life. But no one in the health system talked with him and his family about all the choices — so, naturally, as his illness marched ahead there was some friction over how far, how heroically, his doctors would treat him.

In time, the family contacted a palliative care physician who could talk with them about easing her father’s pain rather than trying against hope to extend his life. It was late for that talk. Her father fell into a coma the night before the appointment.

But they had it nonetheless as he lay in an intensive-care unit. “We all came together,” Yedlin said. Minutes later, as if by signal, her father went into cardiac arrest.

An emergency team rushed to the room. The doctor waved them off.

“They were kind of disappointed,” Yedlin said. “They were going to go in there and probably crack open his chest and start his heart up. That is what they were trained to do.”

The family gathered by his side. “Within two or three minutes the breath, and the life, flooded out of him,” she recalled.

That was in 2004. Yedlin, who lives in New Haven, told the story Wednesday at a gathering of health practitioners on that excruciating subject — advanced illness care, or how to treat patients at the end of their lives.

She was part of the kickoff event for an effort at the Connecticut Hospital Association called “Care Decisions Connecticut,” which aims not to cut off aggressive care, but to help families and patients receive the treatment they want and not the treatment they don’t want but think they should have.

That requires really hard conversations. The big message is, it’s never too soon to talk about it.

“What we really want to create is a social movement,” said Dr. Adam Silverman, vice president of continuing care and chief population health officer at Trinity Health-New England, the Catholic church-affiliated chain that owns St. Francis Hospital and Medical Center.

“We have to get into the community and we have to get in to people’s homes,” said Silverman, co-chairman of Care Decisions Connecticut. “‘Hey Mom, hey Dad,’” he intoned, “what do you really want?”

The hospital association’s effort is part of a national movement led by health care providers — not, for the most part, health insurers. But make no mistake, if this social movement, this cultural change, takes hold — the way it has long been a way of life and death in much of the world — it could save hundreds of billions of dollars every year in the United States.

You won’t hear these people talking about controlling costs, at least not as the main goal. Nope, no death panels here — savings is a distant, secondary benefit in this movement.

“Patients are dying in the environment they don’t want to be dying in. They’re dying in hospitals, all because we’re not asking the right questions,” said Karen Mulvihill, director of palliative care services at Western Connecticut Health Network, comprising Danbury, Norwalk and New Milford hospitals.

“It’s not about ‘let’s limit care,’” said Kevin Lembo, who, as state comptroller, is basically Connecticut’s largest buyer of health services.

Continued on next page
Even though this isn’t about saving money, paring the nation’s $3.4 trillion annual health care bill is the only way out of America’s health coverage crisis, as Obamacare and private-market plans rise in price and Republicans including President Donald Trump vainly say they can deliver better coverage for more people at lower prices.

If voluntary efforts like this don’t work, the medical access system will need to impose more restrictions on some patients.

That might sound inhumane but we’re already forcing tradeoffs. Aggressive end-of-life treatment is a big factor in astronomical insurance premiums and government payments — which, in turn, price millions of people out of health care.

The philosophy behind Care Decisions Connecticut is to avoid coercing patients and families. “If they want full treatment, we’re still with them,” said Mulvihill, the co-chair along with Silverman.

You might think enlightened Connecticut, home of the nation’s first free-standing hospice in Branford, would be ahead of the curve. In fact, the state is in a three-way tie for last place in the percent of patient-days in hospice care in the last six months of life.

It’s not a lack of hospice beds, Silverman said. “Patients are choosing life-prolonging therapy care for a longer period of time.”

Reversing that culture requires fighting a slippery enemy. We all know that when given a stark choice, just about everyone would surrender to a peaceful end with dignity over a mechanically extended life with zero quality. That’s not so easy when the moment arrives in a system with powerful moral, financial and emotional forces all trying to beat back death.

For providers, the question is how to measure success if it isn’t all about defeating disease.

Dr. Margarita Reyes of Bristol Hospital told a story that showed she should have talked sooner with a family about a dying patient’s end-of-life care, as they thought she was giving up too soon. “I don’t consider myself a failure as a physician if death is the outcome,” she said.

Yedlin, whose father died in the intensive-care unit, is left wondering what might have been if the conversations had happened sooner.