The Colorado Health Foundation™

Easing the End of Life with Conversation

A Unique Project Encourages Families to Talk about the Unmentionable

As ethics consultants, Constance Holden at Boulder Community Hospital and Jean Abbott at University Hospital in Aurora are often called on to help resolve conflicts that arise when family members disagree on how to care for their loved ones who are nearing the end of life.

“I have witnessed many difficult situations that might have been averted or been less difficult if the patient had had a conversation with family about their wishes,” said Holden, a retired registered nurse and co-founder of The Conversation Project in Boulder County, whose mission is to foster meaningful and effective conversations about end-of-life care.

According to the Institute of Medicine, many people may not be able to physically or mentally communicate their wishes regarding care when they are nearing the end of life. And while 82 percent of Americans say it is important to put end-of-life wishes in writing, only 23 percent have actually done it. Patients, moreover, often end up in the hospital with a physician who they have never met.

Designating a medical durable power of attorney before a crisis – choosing an agent who is locatable and can speak on the patient’s behalf at those crucial moments – can eliminate these conflicts. “That person is key because of the fragmentation of the health care system,” said Abbott, a retired physician and co-founder of The Conversation Project in Boulder County.

Partnering with the Community Foundation Serving Boulder County, The Conversation Project encourages people to think about, document and, most importantly, talk to family members about their values and wishes regarding end-of-life care. A starter kit (available at theconversationprojectinboulder.org) includes questions that address emotional, medical and practical issues to help guide people in having those conversations.

State – and National – Outreach

The Conversation Project in Boulder County is based on the work of Pulitzer-prize winning journalist Ellen Goodman, who founded the organization in 2012 after the death of her elderly mother. The Conversation Project is supported by the Institute for Healthcare Improvement.

“Jean brought Ellen Goodman’s work to my attention. We both looked at each other and said, ‘This is what people should be doing,’” Holden said.

They believed similar programs across Colorado could improve end-of-life care for people in many communities and prevent the types of conflicts they often deal with as ethics consultants. They asked Goodman if they could use “The Conversation Project” name for their local endeavor.

Goodman agreed, requesting that the Boulder project become a model for other communities, which it has done. There are similar efforts in Weld and Larimer counties and several groups in metro Denver, Abbott said. She and Holden regularly hear from people from across the country seeking information about what’s happening in Boulder County.

We are hoping this will become a statewide initiative,” Holden said. “We’re willing to share everything we have.”

In Boulder County, Abbott and Holden along with a dozen trained volunteers have given nearly 200 presentations about The Conversation Project. They estimate that they have reached at least 2,200 people by speaking at rotary clubs, libraries, senior centers and other venues.

In Grand Junction, Rocky Mountain Health Plans Foundation has twice invited Abbott to speak on the Western Slope to groups that include clergy, social workers, hospice employees and other community members about how to start their own Conversation Project. “Our foundation is looking at taking The Conversation Project into the workplace,” said RMHPF executive director Lisa Fenton Free. “Starting in the fall with our (450) employees, we will hold sessions at workplaces on work time and before and after work.”

In July, RMHPF met with the Coordinating the Coordinators Committee, a Grand Junction group working to coordinate patient care among physicians, agencies and case managers, and bring The Conversation Project into their various worksites. RMHPF also plans to reach out to the Mesa County Health Department to learn about other places in the community where they might introduce The Conversation Project. “We’re excited about promoting these conversations, which will add more meaning to life versus having a fear-based approach to end of life,” Fenton Free said.

Starting the Conversation

For the past two decades, the Mesa County Advance Directives Task Force, represented by Grand Junction’s two hospitals, the county Department of Human Services, RMHPF and other organizations, has sought to educate community members about advance directives, said task force chair Mary Watson. “This year we focused our attention on The Conversation Project” by giving presentations at HopeWest hospice, assisted living centers, nursing homes and Montrose Memorial Hospital.

The Conversation Project is particularly timely since the Centers for Medicare & Medicaid Services recently announced a new policy: The government will reimburse doctors for having voluntary conversations with their patients regarding values and preferences for end-of-life care. The policy is set to go in effect

January 1, 2016, after a 60-day public comment period. A similar provision was initially included in the Affordable Care Act until opponents likened it to “death panels,” claiming, falsely, that the government would be rationing actual health care.

“Frankly, the majority of people who come to our presentations fear they’re going to get too much medical care – life-prolonging procedures they may not want,” Holden said. “The default is that if you don’t tell anyone your thoughts, you will get everything (resuscitation, ventilator, feeding tubes) regardless of quality of life afterward.” The Conversation Project helps people identify what they want, whether that’s aggressive, “do everything” medical treatment or signing a do not resuscitate order.

The Patient Self-Determination Act requires physicians and hospitals to ask patients if they have advance directives or would like information about making end-of-life decisions. “It was supposed to spark those conversations, but it hasn’t happened” because physicians are often uncomfortable broaching the subject, Holden said. “We want the public to have these conversations with family, and then go and talk to their doctor. We’re preparing people to do that.”

> Frankly, the majority of people who come to our presentations fear they’re going to get too much medical care – life-prolonging procedures they may not want.
>
> Constance Holden, ethics consultant, Boulder Community Hospital

Sandy Younghans downloaded the starter kit after her brother Jeff was diagnosed with a rare, degenerative brain disease. The retired Boulder attorney initiated the conversation with her brother by using the starter kit questions to help Jeff identify his goals and wishes for his approaching end of life.

"He was very clear about not wanting any feeding tubes," Younghans said. She discovered her brother's biggest fear was loss of mobility, which explained his plans for knee replacement surgery – a high-risk procedure that would have still left him with tremors, speech problems and prone to falling as well as a lengthy rehabilitation period. After talking with his sister and palliative care professionals, Jeff was able to identify what was most important to him – spending time with family. He canceled the surgery. The conversation with his sister paved the way for subsequent conversations with his wife and daughters.

Retired Boulder physician Carolyn Shepherd learned about The Conversation Project when she heard Goodman speak at an Institute for Healthcare Improvement conference on the East Coast. Shepherd and her husband downloaded the starter kit and answered the questions separately. Though they found the majority of each other's responses not surprising, there were issues that "became clearer for both of us – if ever we're in that position," Shepherd said.

"For example, my husband was adamant about having his loved ones follow his wishes exactly, even if it makes them uncomfortable," Shepherd said. As a physician, she said she expected to make some decisions about his care; but her husband was most comfortable with her promising to not deviate from his wishes. "The degree of importance of this to him surprised me and was something that was critical for me to understand," Shepherd said.

Next, the couple had a conversation with Shepherd's sister. A third conversation is planned with the family's two children.

“One daughter is very uncomfortable (with the topic), but she’s going to do it,” Shepherd said. “It’s very helpful to have a small template to put the conversation into. (The starter kit) is a useful tool.”

The conversation may need to be repeated as plans may change, and the chosen agents may also undergo a switch, Holden said. She emphasizes the importance of having the conversation “upstream” – before a new diagnosis or other medical crisis, when the topic may be more difficult to talk about with loved ones.

“In our capacity as ethics consultants at our respective hospitals, we are often called upon when families are in conflict about the course of action to take when their loved one is unable to participate in decision-making,” Holden said. “Too often we hear, ‘We really don’t know what Dad would want; we never talked about such things.’ Values-based discussions can offer families critical guidance at the bedside. Avoidance of confusion, conflict and heartaches are the goals of The Conversation Project."

This article was originally published in the Fall 2015 issue of Health Elevations.

TYPE

Story

POST DATE

Oct 1, 2015

BY

Sharon Sullivan