Honoring Choices for end-of-life care

By TAMMIE SMITH □ Richmond Times-Dispatch | Posted: Saturday, December 13, 2014 10:30 pm

Harvey Chambers is 54 years old and as far as he knows in relatively good health, but he has thought about what might happen if he develops a terminal illness or life-threatening condition.

“I just did my trust,” he said, referring to a legal arrangement that spells out his wishes. The planning also includes an advance medical directive with his wishes for end-of-life care.

“My brother is my trustee. When I told him about it and that I needed to have a conversation, the first thing he did was look at me and ask, ‘Are you sick?’ He immediately went to this as something that you do at the end of life,” said Chambers, who operates Seniors Helping Seniors, a business that provides companion services and other resources to seniors.

The type of meaningful conversation Chambers plans to have with his brother might be a bit uncomfortable, but it’s the type that medical and ethics experts say more of us need to have — and better now, when we are able to express our values and wishes, than later, when family and health care providers have to guess at what we would want.

Advance-care-planning needs change as people pass through the different seasons of life.

“I’m in my summer,” Chambers said. “I say that because people are living much longer now. What used to be considered fall is no longer fall from an age standpoint. This is the best time.”

Last week, Richmond health system and medical community leaders unveiled a new initiative called Honoring Choices Virginia that aims to make these discussions more common and thoughtful and provide trained leaders who can help lead those talks.
Spearheaded by the Richmond Academy of Medicine, Honoring Choices Virginia has the support and backing of all three of the region’s major health systems: Bon Secours, HCA and Virginia Commonwealth University Health System.

The idea is to get people thinking about what they want to happen if they are faced with decisions about end-of-life care — for themselves or for their loved ones — and to have people and systems in place to help them sort through the options.

As part of the initiative, health care professionals, social workers, chaplains and others are taking special training to facilitate those conversations.

“Every day, ambulances rush very ill people to emergency rooms all across our community because of serious medical crisis or injury like a stroke or auto accident,” said Dr. Richard Szucs, a radiologist with Commonwealth Radiology and immediate past president of the Richmond Academy of Medicine. The initiative got started under his leadership.

“The patient arrives at the hospital, and they can’t speak for themselves. The health care team that’s treating the patient doesn’t really know the values, beliefs, priorities or wishes of the patient. The next of kin may arrive, but the loved one really doesn’t know what the patient wants because they haven’t had a conversation. Would they want to be kept alive on a breathing machine? Would they want to have a feeding tube? They feel very unprepared to make those decisions for the individual. Then as other family members arrive, they continue the conversation. And since no one really knows, there may be conflict between the family members, which is additional stress at a time like that and can really tear the family apart,” Szucs said.

“If we want to change that type of a dynamic, we really need to help individuals and their families create plans further in advance for complex health care decisions like that. And we need to redesign the health care system so that it becomes just a routine part of good medical care to have individuals talking about their values and goals and beliefs.”

Honoring Choices Virginia has been more than a year in development. It integrates elements of efforts such as National Health Care Decisions Day and The Conversation Project, but reaches further than both.

**Making health care decisions**

Estherine Crowder, 51, a single parent of a 16-year-old, is battling ovarian cancer.

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**Barring some** game-changing biomedical development, all of us are going to die.

But people don’t necessarily like to think about it or talk about it or prepare for it, according to
national polls and a recent report called “Dying in America” from the Institute of Medicine, an independent, nonprofit organization that gets about half its program funding from federal sources.

“Even though death is very much part of the cycle of life and the journey to physical dying begins with the inception of living, thinking and talking about one’s own death usually remains in the background, at least until its prospect become more probable or imminent,” leaders in the Institute of Medicine effort wrote in the preface of the 500-plus-page report released in September.

The report calls for measures to improve quality of care at the end of life and for measures that honor people’s preferences and values. It also references the controversy and politics that continue to be impediments. The backlash against so-called “death panels,” for instance, pretty much quashed efforts to include provisions in the Affordable Care Act to pay doctors for having discussions about end-of-life care with Medicare patients.

“Efforts are needed to normalize conversations about death and dying,” says one of the many recommendations in the report.

“It happens to us of all. Your body is going to wear out,” said octogenarian Cliff Edwards, who got one of the biggest laughs of the afternoon at this month’s Richmond Times-Dispatch Public Square, which explored how to make the best of one’s golden years. Edwards said he was there to “put in a word” for illness, death and dying.

“Death is a real thing, and why don’t you spend some time talking about it sometimes?” said Edwards, 82, a world studies professor at VCU.

Why not? Superstitions. Fear. Not knowing how to have the conversation. Not knowing the language to use so as not to turn people off.

But people don’t have their heads totally in the sand. A 2013 Pew Research Center survey that captured how Americans feel about end-of-life medical treatments found that 37 percent of adults had given a “great deal” of thought to their wishes for end-of-life treatments, 35 percent had given the topic some thought and 27 percent had thought very little or none at all about end-of-life care.

About a third of the adults surveyed had put those decisions in writing in formal or informal documents.

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The uncertainty over end-of-life medical care and interventions is to a large degree a modern phenomenon. People used to die at home in the care of family. If a person suffered a life-threatening injury or condition and was hospitalized, there wasn’t the expertise or technology to keep them alive like there is today.

“I like to say that we are the first human beings to have to address this issue,” said Bernard Hammes,
director of Medical Humanities and Respecting Choices for Gundersen Health System in La Crosse, Wis. Honoring Choices Virginia is modeled after Respecting Choices, and Hammes helped local leaders develop the Virginia program.

“These kinds of decisions were not typically even faced by our parents 20 years ago. This has been an emerging problem over the last 20 or 30 years. It slowly has come up, but it’s become a widespread problem,” Hammes said.

“The pain that people are suffering from this uncertainty about what to do is widespread, and in many cases it’s quite severe.”

The challenge, Hammes said, is to get people and systems to change.

“This is really about a cultural change. It’s really a switch of understanding about what it means to take good care of people. In this case, what we’re saying is taking good care of people requires us to start with an understanding of who the person is — what is important to them as individuals who have family relationships and other values and goals and religious beliefs. It’s really an effort to transform the health system so that it is focused on the delivery of high-quality care in an individualized fashion,” Hammes said.

It is not rationing care or convening panels that decide if a person’s life is worth saving or continuing, those involved said. If people want aggressive measures to save their lives, so be it. If they have a terminal illness and want to forgo another surgery or another experimental medicine, then that is OK, too.

As part of the rollout of the program in the Richmond area, the three health systems have each identified three locations that will participate.

At the VCU Health System, Kenneth Faulkner, a chaplain at VCU for the past 24 years and former director of pastoral care there, was recently named the health system’s advance care planning coordinator, a newly created position.

“We felt this effort was so important, our leadership did,” Faulkner said. The VCU team also includes their palliative care director and a Massey Cancer Center administrator.

“We’ve got 10 persons we are going to train as facilitators. They will receive training in how to have thoughtful conversations with patients and families that will lead to the creation of an advanced-care plan,” Faulkner said.

Those staff members will work at outpatient-care locations. Honoring Choices Virginia aims to work with people who are not currently facing life and death decisions.

“It’s for folks who are relatively healthy. Ideally everyone who is 18 and older should have a basic set of advance directives in case of an unexpected medical emergency,” Faulkner explained. “With
our Honoring Choices program, we are looking at individuals who may be 50 or 55 or older, but patients we are already seeing in different clinical settings with ongoing medical problems, ongoing chronic problems, but who aren’t yet in an emergency situation.”

Plans are to reach out to the faith community, employers and community groups, Szucs said.

“As we move forward with this, we envision that it’s really a matter of changing the whole culture. So it’s not necessarily something that would take place in the health care system only. ... In the later phases of this, we would see training additional facilitators to do this in other settings, perhaps in churches or businesses.”