

End-of-life programs help bring closure to patients, caregivers

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By Pohla Smith, Pittsburgh Post-Gazette



Robin Rombach/Post-Gazette

Dr. Jonathan Weinkle, right, talks with patient Charlie Roth at the Squirrel Hill Health Center.

In going about its 20-year mission of delivering services to the elderly and chronically ill, the Jewish Healthcare Foundation noticed something missing.

"[They] were talking about growing older and people getting sicker but never mentioning death or dying," said Jonathan Weinkle, a pediatrician and internist doing primary care and chronic disease management at the Squirrel Hill Health Center. He serves as a medical adviser to the JHF.

"It seemed that was a natural part of conversation that was not being brought out [and] it didn't make sense ... to not talk about what happens when you come to the point where you're going to die, and that needed to be dealt with." That glaring absence of conversation was brought up to the JHF board, and an end-of-life initiative called Closure was born. It started with Closure Community Conversations followed by a second component called Closure 101. Now a third has been added, a Closure website: www.closure.org, which was launched Friday. In related end-of-life projects, the JHF also has funded a WQED documentary and commissioned a book of creative nonfiction. Both are due out this spring.

The JHF's "ultimate goal is to take this goal of creating an environment of where people can state their [end-of-life] wishes and have them followed through [and] create a national movement," Dr. Weinkle said.

But it all began with the community conversations.

The conversations, of which there have been three since November 2007 and with more on the way, are a series of six discussions designed to spark a dialogue about end-of-life issues within specific communities. They bring together such people as health-care professionals, clergy, financial planners, hospice workers, lawyers, social workers and family caregivers.

They have resulted in, among other things, useful information on services available and the differences between palliative (improving quality of life for those facing serious illness) and hospice (for those in the last months of life) care; talks about the failure of health-care professionals to address end-of-life issues with longtime patients; and sharing of personal experiences.

The discussions led to Closure 101, a curriculum of lessons that can be used online or in person to educate consumers and health-care professionals about end-of-life issues and options.

"What we've gotten out of [the conversations] so far is that there is a basic need for education first and foremost for a lay person without medical or legal knowledge to understand what death and dying entails for the family member," Dr. Weinkle said. "That's what led us to develop the Closure 101 curriculum."

Twelve lessons from Closure 101 are included on the new website, along with a personalized self-assessment that pinpoints what lessons most fit a user's needs. Other contents include a Southwestern Pennsylvania Resource Directory; links to national organizations dealing with end-of-life issues; tip sheets; reference materials; a national news feed; and blogs for consumers and professionals.

"One of the nice things we've done with the 101 curriculum is collect lots of needs in bite-sized pieces so people can go and take their assessment and customize their line of learning and get what applies to them," said Dr. Weinkle, a key developer of Closure. For example, he said, someone here caring for an out-of-state patient can visit a module on long-distance care-giving.

Available for downloading is a form for ordering a manual the JHF developed on how to set up a Closure Community Conversation, something Jefferson Regional Medical Center's Palliative Patient and Family Support Services unit is planning to use for its own neighborhood series this spring. "We will adjust it to our community needs, but they have it nicely formatted so I think it makes our task easier," said Dr. Uzma Khan, medical director of the palliative care unit.

A conversation also is being planned for local veterans, and a speakers bureau is developed for use in future series. Closure's first two conversations were within the Jewish community, but, Dr. Weinkle said, "it was clear from the time we started the conversations it would move beyond the Jewish communities."

The third conversation, held from November 2009 through April 2010, was convened by Allegheny General Hospital and the North Side Leadership Conference with JHF support. Designed to engage the North Side's African-American community, it was co-chaired by Doris Carson Williams, president and CEO of the African-American Chamber of Commerce, and lifelong Manchester resident Michelle Jones.

The JHF asked AGH and the Leadership Conference to hold the series after watching them bring in as a community program a dramatic reading of Bryan Harnetiaux's "Vesta," a play about a family dealing with the end of life of its matriarch. The longtime North Side partners, who saw 150 people attend "Vesta," agreed.

"We thought [the attendance] showed a lot of interest in the topic to address issues surrounding end-of-life care," said senior AGH vice president Debra Caplan.

About 30 North Side community leaders attended the Closure conversations.

"It was probably one of the most enlightening workshops for lay people to participate in," Ms. Williams said. "It was important because as we start to take care of elderly parents and allow them to make decisions [about their final years] ... we're also there to provide quality of life."

During the community sessions, participants come to findings or conclusions. In Closure III, for example, North Side participants concluded racism affects end-of-life planning and decision-making.

"There's a major disconnect between the medical profession and the family, and a number of participants raised this issue," Ms. Williams said. "They thought ... there was a lack of sensitivity."

Retired oncology nurse Pearl Moore of Shadyside attended Closure I with two perspectives: One as a daughter who lost her mother to stomach cancer back in 1970, a time when, she said, dying was just not discussed, and the other as former CEO of the Oncology Nursing Society watching that mind-set change.

"Some people in more recent years want much more information, and they know about getting that information," she said. "... Some don't want to know too much, and I think it's a professional's role to understand that."

Findings in Closure II, according to the JHF, "highlighted the need for a public awareness campaign ... designed to change the default from doing *every* thing to doing the *right* thing."

It is a belief Jefferson Regional's Dr. Khan shares. "Without palliative care ... the medical system would have such failure to have conversations about what is good for the family and provide everything under the sun," she said. "At the end they have these conversations ... when it's an emergency situation and families are not prepared for this. They feel they have to continue to fight for their loved ones, and [they] make a decision that may not be appropriate. ..."

"Sometimes physicians feel like a failure, like they're giving up -- when it's not, because it's people looking for a recommendation to figure out what they can do in an environment where you can't do a whole lot."

Closure is designed to help people avoid such difficult situations, Dr. Weinkle said. "We're trying to perfect how we care for people right up to the last moment of their lives."

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