Finding Grace

Palliative care program intended to ease the suffering associated with end-of-life stresses

Medical and social workers are setting up a network and training system to help dying people define their own end-of-life choices — so families and caregivers can move forward knowing where death should take place, who should be there, how pain should be handled and where money should go.

By JOHN DARLING

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Medical and social workers are setting up a network and training system to help dying people define their own end-of-life choices — so families and caregivers can move forward knowing where death should take place, who should be there, how pain should be handled and where money should go.

The program, called Choosing Options, Honoring Options, is designed to overcome widespread resistance to the discussion of such issues, opening the way for dying people to be in charge of their own end-of-life choices by writing "advance directives."

The process is designed to be accessible, with a social worker present, initially, 12 hours a week in selected physicians' offices, said COHO Chairman Dr. John Forsyth, a retired cardiologist.

COHO, which is part of Jefferson Regional Health Alliance, Friday received a $92,500 grant from the Regence Foundation of Regence Blue Cross-Blue Shield of Oregon to do community education, outreach to physicians and start a pilot program for social workers placed in Providence Medical Group Doctors Clinic, said Maddie Andrews, program officer for Regence.

"People don't know what palliative care is yet — and physicians don't have time to do it," said Andrews, who presented the grant at a meeting of JRHA at Rogue Valley Manor.

Palliative care means treatment to relieve suffering, she said, and includes relief from end-of-life choices that can be complex and troubling if not addressed early on.

"It's a major movement in the medical profession and our society as a whole," said Forsyth. "As our population ages, we see a lot more people confronted with problems about what kind of care they want at the end of their lives. This may be the first time in history people truly have a choice over the kind of care they receive at the end of life."

A recent study by the University of Michigan, he added, showed that 70 percent of people in their last three weeks of life are incapable of participating in discussions about end-of-life choices. "So unless we have the discussions early on about their preferences, they end up with the default situation, which is to give aggressive care that is unnecessary, ineffective and only prolongs suffering," he said.

The program, said Forsyth, will help overcome the misconception that dying people can get expensive, high-tech care or palliative care — but not both.
"The goal is to facilitate an open conversation about end-of-life care for the (dying) people themselves, with family, friends and caregivers and with the community," he said.

The program has tools to help open the conversation about end-of-life choices, including a card game, with cards representing all possible choices, which the individual can sort into categories of importance, then moving on to writing advance directives for all to follow, said Anne Alfinte, a physician and project coordinator for JRHA.

"It challenges people around death in general, so they can face fears about it," said Alfinte. "The hope, with COHO, is to create the space and safety to bring joy and grace to the process. It brings people together in intimacy of conversation with loved ones. You talk about what's meaningful to you — if you want music; what people are going to be there; whether you want to die at home; the big question of not being a burden to others."

"You have peace at the end of life," Andrews said. "It's the opportunity not to have unanswered questions."

"Our culture is shifting, and a lot of people want to have this discussion," Forsyth added. "It's a quality of life issue."

"It's more about living than dying," said Susan Hearn, COHO program manager, "because you are getting and using the information you need to be self-determined. The medical aspects are being taken care of, the symptoms and pain are under control.

"You can focus on what's important to you. The person leaving this world has the chance to say, 'I love you' and 'I forgive you.' It's a gift to the dying person and their family."

COHO is composed of 100 volunteers from 25 organizations in the region.

Its partners include the Gordon Elwood Foundation, Northwest Health Foundation; PrimeCare; Southern Oregon Friends of Hospice; Providence Medford Medical Center; Rogue Valley Medical Center; hospice programs of Asante, Ashland Community Hospital, LoveJoy and Providence; palliative care programs of Asante and Providence; and Providence Medical Group.

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