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HEALTH BEAT: END OF LIFE CARE

Vigil programs offer comfort for dying

By Julie Deardorff

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The dying woman did not want to be alone. So Northfield's Alan Ortiz read her poetry written by Rainer Maria Rilke and Robert Frost. He played Japanese flute music. And he sat quietly as she drew her final, raspy breath.

"It's a humbling, timeless moment," said Ortiz, 41, a volunteer at Midwest Palliative & Hospice CareCenter in Glenview who does vigil work. "Sometimes I ask myself, 'What if the roles were reversed?' I know I would want someone there."

A consultant by day, Ortiz also is part of a movement dedicated to providing terminally ill patients companionship at their time of death -- if they or their families have requested it.

While many of the vigils are held in hospice settings, programs such as No One Dies Alone, which began in an Oregon hospital, are spreading to hospitals, nursing homes and long-term care facilities across the nation.

"Typically at the end of life, people's biggest fears are being in pain and dying alone, so we do our best to address those fears and replace anxiety with comfort," said Dave Maly of Horizon Hospice and Palliative Care in Chicago.

At the CareCenter, vigils are held if the patient has no family and has indicated he doesn't want to be alone. Other times, a volunteer is called in because there has been a change in condition and an out-of-town relative is flying in to be with a patient. Volunteers also can sit with the dying when relatives and friends are emotionally or physically exhausted but reluctant to take a break.

"Vigil programs are much more about the family's needs and fears about being alone than the person who is dying," said CareCenter senior clinical director Julie Bruno. "When people sit

vigil, there's a tendency to want to be right on the bedside. Sometimes we'll flip our hands under their hands; it gives us an indication of whether they want you there, and we can back off or engage in the touch. We teach families to do the same."

Chicago's Kathy Gaspar, 40, sat vigil with her father for three days and was able to hold his hands as he took his final breath about a month ago. But she agrees that her presence helped her own peace of mind more than it helped her father.

"You always hear people say, 'Well, I'm glad that they did not die alone,' but when you are as sick as my father was at the end and are no longer conscious of your surroundings, you're already getting ready for a place of eternal rest," she said.

There also are times when people simply don't want companionship during their final moments, said Martha Twaddle, CareCenter chief medical officer.

Back in the 1990s, Twaddle and colleagues noticed families would be in a bedside vigil for days.

"When they finally went to get some dinner or take a shower, the person would die," Twaddle said.

An informal survey told them that more than 80 percent of the time, moms died alone. Dads, on the other hand, seemed to wait until everyone was there and died in the midst of the gathering, Twaddle said.

"Even when the family was in vigil, it was when they left that Mom died," Twaddle said. "What does that perhaps indicate about wanting someone there?"

For anesthesiologist Martin Flynn, 52, of Marina Del Rey, Calif., the answer is a hearty yes.

"The people who love a crowd in life should get the crowd, but those of us who toil quietly will not want a lot of undue attention headed our way," he said. "Just slip on a set of earplugs with iTunes and let your [favorite] music ease the passage."

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'For me, a death is a very holy time'

'A young man in his 50s had a broken family relationship, and people were afraid to be around him in the final days. I didn't have to stay long, but it was a very personal experience. For me, a death is a very holy time, and I literally had the sensation that I wanted to take off my shoes: I was on holy ground. That's as close as we get to that transition while still being able to talk about it with friends and loved ones. I was able to share the experience with the man's

family at the funeral. It was a wonderful experience for me and I hope for them as well."

-- Julie Bruno, CareCenter senior clinical director

'A [dying] man's wife and daughter left to get something to eat. It was the last half-hour before his passing, and the son was [in the room] on his cell phone. I could see it was the son's anxiety and fear -- he had to have something to do. I finally said, 'Let me take your phone call.' I turned it off, guided him to his father's bedside and said, 'You can talk to him. Just tell him what you need to say.'

"'I will take care of Mom,' he finally said. 'I'll take care of my sister. It's OK.'

"He professed his love to his father and had that last conversation. I think about what the death could have been. ... You can change someone's memories and the course of their bereavement by changing those few actions. We don't know how to be with someone when they die. Let's put the phone away, let's sit and touch and say what needs to be said. The son knew what to do but didn't have the permission and guidance. Those are the things that those of us in the field find profound. It does change someone's life."

-- Elizabeth Shinar, director of volunteers at CareCenter

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