

May 2019 LeadingAge Catalyst

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Learn more about LeadingAge's Catalyst for May 2019: the Vigil Volunteers at Carleton-Willard Village in Bedford, MA.

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The 2018 Carleton-Willard Vigil Volunteers. Alice Morrish is seated on the left in red. Marcia Feldman, in red, is standing at the far left, and Barbara Doyle, president and CEO, is standing at far right.

Innovation in Volunteer Services

Living Fully, Dying Well® is the palliative care program at **Carleton-Willard Village**, a life plan community in Bedford, MA. The program offers physical, emotional, and spiritual support to people

approaching the end of their lives, and to their loved ones. Employees have ongoing educational opportunities available to hone their skills in caring for the dying, and they are encouraged in self-care techniques. Carleton-Willard also partners with 2 area hospice providers to serve patients who need or want hospice services.

Our choice as this month's LeadingAge Catalyst is the Vigil Volunteers, a very important part of the Carleton-Willard program. This group of trained volunteers—most of them Carleton-Willard Village residents—sit with patients and families as needed, offering a quiet and comforting presence at the end of life.

“A central goal of our program is that no one should have to die alone unless that is their wish,” says Marcia Feldman, palliative care coordinator. “Sometimes family can't be there, or they are far away. Whatever the situation is, we try to have a support system for them.”

Even with family present, Vigil Volunteers can fill in for them if they need to go home to shower, eat, or take care of other business. Some Carleton-Willard CNAs are trained as well, and Vigil CNAs can fill in during overnight hours.

The Volunteers

There are about 24 active Vigil Volunteers, 2/3 of them independent living residents at Carleton-Willard, and the rest drawn from the surrounding area. Feldman says potential volunteers reach out to her; Carleton-Willard seldom, if ever, needs to recruit.

One resident volunteer, Alice Morrish, explains the appeal and the difficulty of the work: “The best thing I get out of it is when I feel I've made some kind of connection with the person, and said something meaningful or asked something that elicited a smile or nod. The hardest thing is that though I understand death is part of life, I feel sad when somebody dies because it's a life ended. Though there is sadness, the process of being with a person while they are dying is very meaningful to me.”

Morrish, who has been a Vigil Volunteer for about 4 years, says she will typically spend about an hour at a time with a patient, but the vigils vary from case to case.

“One thing I have learned is that death and dying is a very individual process,” she says. “You’re never sure, until you meet the patient, exactly what your role will be. Sometimes you’ll talk, or just hold their hand, or sit quietly and listen to music they’ve chosen, or read aloud. One tries as hard as one can, because sometimes patients are not very verbal when they’re quite ill, to figure out what will work with an individual.”

Feldman tells the story of one Vigil Volunteer who contemplated quitting: “She told me, ‘I’m 93 and I can no longer drive, I can’t see or hear very well, I can’t walk without a walker, and the list goes on. But I can still sit and hold someone’s hand while they’re dying.’ And with that declaration, she decided to stay with the group.”

Feldman says she has seen volunteers sit vigil on holidays and birthdays and give up time with their own families to be there for others.

Morrish tells one story illustrating how important it is for Vigil Volunteers to just listen. “A young man came to visit his dying uncle. He was a little awkward and jaunty at first, but the patient wasn’t very conscious. Gradually the nephew and I talked about his uncle’s life and accomplishments. It was a safe space where he could talk about how much his uncle meant to him as a child and now as an adult. I think that really helped him. It was very rewarding for me, too.”

Training

Feldman and Lee Steppacher, vigil volunteer coordinator, run the program and train the volunteers. Feldman says the 8-hour trainings are held every few years, and a recent training brought 6 new volunteers into the program.

The continually evolving curriculum includes:

- How to be a presence for those at the end of life.
- Exploration of the volunteers’ own fears, thoughts, and wishes around their own deaths.
- Learning about some of the physical symptoms of dying.
- Spiritual practices in different faiths, and emotional stages people may go through at the end of life.
- Current research, resources, and philosophies about the end-of-life care.

- Role-playing exercises, which Morrish says were especially helpful to her while in training.
- Exercises designed to make people more comfortable with death, so they can be present to those nearing death.
- A video available on YouTube, [Angola Prison Hospice: Opening the Door](#)—a moving story about the development of a hospice for inmates who will die in prison.

One of the most significant elements of training, says Feldman, is the “loss exercise.”

“We ask the volunteers to write about aspects of their lives that they cherish (loved ones, possessions, favorite activities, etc.),” she says, “then we simulate taking each of these away from them during the exercise. We have found that when a person relates loss to their own experience and imagines how they would feel having to let go of everything they hold dear to their hearts, as the dying must do, it is the quickest and most powerful way to cultivate compassion for others. This exercise demonstrates how arbitrary loss can be, and how difficult it can be to cope with, by allowing each person to relate it to their own situation.”

Feldman notes that hospices are required to have a certain number of volunteers, but that it’s unusual to run such a volunteer program with in-house residents.

“That’s key, that it’s very meaningful for residents that volunteer in this unique way,” Feldman says. “Some of them have known the people that are dying for many years, so they sit vigil with the depth of their shared history and friendship in their hearts.”

Morrish says, “I think there’s something very special about seeing someone you have known, even if you haven’t been best buddies, and to be with them as they are going through the process of dying.”

Morrish adds that families benefit as much as the patients: “First, you’re able to give them a break; and you can also sometimes talk about the loss that they’re living through. It’s amazing to me how deep the appreciation is [from] the families in the program. It means so much to them to know their loved one is really central to us.”

Living Fully, Dying Well was conceived after the death of Carleton-Willard CEO Barbara Doyle's mother, who lived in the memory care unit at the community. The experience led Doyle to envision an end-of-life program and create an interdisciplinary team to develop it. Judy Krumme, a minister who came in as a consultant, and Barbara Chenoweth, a nurse practitioner on staff, led the team and brought their vision—including the Vigil Volunteers component—to fruition.



Comfort baskets for families or vigil volunteers include things such as handmade prayer shawls, a Bible, a book of poetry, music CDs, and more.

Feldman, who had been a contractor who visited to play music for residents at the end of life, was brought on board right before Living Fully, Dying Well was launched in January 2009.

“There have been more than 1,100 Vigil Volunteers visits in the 10-year period [since then],” says Feldman. “It’s not just the dying people who volunteers sat with, but the families that were helped by the Vigil Volunteers’ presence. [There are] concentric circles of influence that go out to the people that benefit from this.”

In addition to palliative care coordination, Living Fully, Dying Well offers participants a wide array of complementary therapies and services:

- Massage, Reiki, acupressure, and acupuncture.
- Music at the bedside.
- Pet therapy.
- Spiritual care provided by chaplains, who can arrange help for patients in any religious tradition.
- The Legacy Project, which brings in a professional videographer to create documentaries about

patients' lives.

“This calls on all of us, volunteers and staff too, to tune in and use all of our skills of perception so we know when families need to talk or not talk, or when it’s time for us to stay or leave the room. It calls on our sense of common humanity and all the skills we’ve developed throughout our lives to be sensitive to the needs of people at this delicate time,” Feldman says. “It’s rewarding because of that.”

If you'd like to recommend an organization or an individual to be recognized, [fill out the nomination form with details about why your nominee deserves recognition](#). The form will require you to log in to your My.LeadinAge account. If you don't have one already, creating one is easy.

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