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Hospice: Love in action



Shannon Ryan, a harpist, is a hospice music therapist who has played a 45-minute session on a small harp to a woman, 91, every day for the past three months. Photo by Jeff Noedel

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by Jeff Noedel Contributor

Combed rays of sunshine descend through the blinds onto a frail 91-year old woman who lies in her bed in a state-certified adult care home in Cape George. She is dying.

Beside her sits Shannon Ryan, a harpist, who has played a 45-minute session on a small harp for the woman every week for the past three months. Ryan is a hospice music therapist, a demure young woman whose voice is so soft she can barely be heard.

She has watched the patient's condition deteriorate over that time. On this day, Ryan knows this may be her last session playing for the dying woman. The woman can no longer physically respond to the celestial version of "Amazing Grace." Her breathing stops for 5 to 10 seconds at a time.

"Today, she was already moving to a place of surrender and pause," said Ryan. "I've been with a few people who took their last breath while I was playing. It creates a sense of sacredness that only strengthens my own faith."

This is the kind of intensely personal, transcendent care being provided by Jefferson Healthcare Home Health & Hospice (known as the agency) and the Hospice Foundation for Jefferson Healthcare (known as the foundation), a 501(c)(3) non-profit.

SIX MONTHS

Hospice is for people with a terminal diagnosis, a prognosis of six months or less, who have elected to stop curative care, and who want to spend the end of their life at home. Patients are encouraged to start hospice care as far as six months out, but some patients come into hospice just days before their death.

"The number one patient objective of hospice is comfort," said Stephanie Tivona Reith, the agency's bereavement support coordinator & chaplain. And the number two patient objective is dignity."

Reith said peace often comes with hospice care, but it is not an objective. Some people, she conceded, die with anger.

Tom Duke, foundation board member and a psychotherapist, said, "Behind anger is fear. We try to normalize it and say, 'Yeah, you're pissed. I would be, too.'"

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Duke added, "Dying people commonly have three fears: dying alone, dying in pain, and dying in an impersonal facility. Hospice can take care of all three."

Said Reith, "We understand the dying process is the single most stressful process a human goes through."

But hospice is not just for the patient. In fact, an almost equal portion of time and resources are devoted to the dying person's caregivers, most often family members.

IN-HOME NURSING

Hospice workers provide in-home nursing care. They teach caregivers how to care for a dying patient, and what to expect in the final days and hours. Hospice volunteers will sit with the patient for a few hours or a day so caregivers can have a break and leave the house, maybe see a movie. If desired by the patient, a chaplain provides spiritual support to the patient and the caregivers.

After the patient dies, bereavement services, in the forms of one-on-one counseling, family counseling, or group meetings, are offered to the survivors for up to 13 months after the patient's death, long enough to get the survivors past the first anniversary of their loved one's death.

"We have no spiritual agenda," said Reith. Hospice chaplains have to be able to support all faiths. And even when a person is agnostic or atheist, Reith said there is often "an internal spirit."

"Ninety percent of the work of a chaplain is listening," said Reith. Patients struggle with doubt, and with questions like "why me," and "why now?"

Like so many people involved in hospice, Reith's demeanor is tender and soulful.

Reith began as a hospice volunteer in the 1990s. She said her work with dying people almost never makes her angry. But she does get sad. Asked if her work makes her cry, she said, "Yes, a lot."

CONNECTIONS

Hospice workers and volunteers form tight bonds with their patients, their caregivers, and each other. Once a year, they hold a memorial service at the

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Quimper Unitarian Universalist Fellowship, remembering those who died in hospice the previous 12 months. This year's ceremony was held Thursday evening, Oct. 30. Former caregivers, with the help of volunteers, light candles and pin notes and photos to a quilt. The quilt with the remembrances is displayed at the agency offices all year.

Four days before Thursday's ceremony, Reith and four hospice volunteers performed a poignant ceremony in a conference room at the agency. One at a time, they removed last year's remembrances and read them aloud. Each remembrance was placed in a large envelope, to be saved for posterity.

Reith later said, "We were clearing the items and energies from the quilt with the same amount of emotion as they were affixed."

As many remembrances were lovingly removed, memories were triggered. Reith and volunteers were reliving some of the losses they felt in the previous year. After all the remembrances were removed and carefully stowed, Reith sprayed lavender perfume on the quilt so as to "clear the energy and ready the quilt for its next purpose."

At the indoor ceremony, another 150 names were read aloud and several dozen names were spoken spontaneously from the audience. Scores of remembrances were pinned to the quilt, and scores of candles were lit.

And the hospice work goes on.

STRONG SERVICE

The hospice program's census fluctuates. In August this year, 37 local people were in the hospice program. The average census in 2014 has been 26 per month, so far.

"The Port Townsend hospice folks do a wonderful job," said Mark Harvey, regional director for information and assistance, Olympic Area Agency on Aging (OAAA). "A lot of folks just feel better by extricating themselves from the medical machine, and spending that time with their family."

MaryAnn Seward is president of the foundation. Seward's passion for hospice work began in 1975, when she saw a presentation at a conference.

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"Hospice humanizes the dying process," Seward said. "Anything we can do to promote comfort, from massages to live music to haircuts and nail care.

President Seward has special praise for Lisa Holt, the agency's new executive director. Said Seward, "Lisa is truly a visionary. . .a woman of dedication and passion to this season of a person's life."

A registered nurse for 24 years, Holt moved in May 2013 from Florida to Port Townsend to run Jefferson Healthcare's hospice and home care departments.

For several years in her nursing practice, Holt cared for critically ill babies. She said babies died in her arms.

Said Holt, "It's a sacred place we're allowed to be in. A holy space."

FREE SERVICE

Today, Jefferson Healthcare's hospice program is at its zenith, and may get even stronger in coming years.

The Foundation, which just celebrated its fifth anniversary, works seamlessly with the agency to coordinate some of the best hospice care in the region.

Medicare reimburses the hospital for many of the services. This year's budget for the hospital's part of hospice is \$1,075,000. The rest of the costs are defrayed by the foundation. Foundation leaders are grateful for the community's support of its annual fund raising breakfast, which netted \$19,000 this summer. So far this year the foundation has received donations ranging between \$10 and \$400,000.

The hospice patient pays nothing for these services.

Home health and hospice care is offered to residents of East Jefferson county, from Port Townsend down to Mason county line, and over to the Clallam county line.

The hospital's hospice staff totals 14 full-time employees, including Holt. Other agency employees include four nurses, two chaplains, and a social worker.

The foundation is run by a 10-person volunteer board and 40 volunteers. The foundation has no employees.

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Kolby Mertz is the hospice volunteer coordinator. She said they are always happy to welcome a new volunteer into the fold. Mertz said the key qualities of a hospice volunteer include nonjudgmental patience, flexibility, reliability, and compassion.

Due to the foundation's successful fund raising and substantial donations, the foundation can do more than ever to assist the agency in maximizing the hospice experience for patient and family. The \$400,000 gift from the estate of a recent Jefferson Healthcare hospice patient has the foundation thinking about building a special hospice cottage. A cottage would cost far more than \$400,000, but it would be a good start. Other donated funds have the foundation planning its first "grief camp" for youth who are grieving the loss of a loved one.

'HALLMARK DEATH'

One Port Townsend physician who is supportive of hospice is Dr. Katherine Ottaway, family physician with Quimper Family Medicine.

"Our society has three ideal ways to die," she said. "The 'Hallmark Death' is where you die in a hospice, willing, with forgiveness, carried off by angels. The second is 'Take me, suddenly, with no warning.' And the third is 'I ain't going. I'm fighting this every step of the way.'"

Ottaway said her own sister fought to the end. With stage 3B breast cancer, she fought for seven years. More than \$1 million was spent on the fight. Her sister went into hospice seven days before she died.

Ottaway said there is a big disconnect between the way the medical community sees the end of life versus the way the public sees the end of life.

But Ottaway said that at the end of life, she sees patients pull back on pain meds so they can deal with emotional issues.

She said, "Emotional pain is different from physical pain. People want to deal with the emotional stuff."

Karen Griffith, foundation board member, said, "There is a misconception that many of us will be able to die quietly and suddenly in the night. That is very unusual. For most of us, death is a process. And everyone has a right to a good death."

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For psychotherapist Duke, hospice work comes down to love. He said, "We have to find a way to love our client to help them. Love allows us to move into a nonjudgmental space."

Bob Rosen has produced a 12-minute video entitled "Jefferson Healthcare Hospice – The Help of the Angels" can be viewed here.

<http://youtu.be/3pPRHJRYd1E>

Hospice Foundation for Jefferson Healthcare, info & donations, click here.

<http://hospicefoundationjhc.org/>