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Dying well

Facing reality head-on, and at home, can make last days not so scary

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Savoring life's last stages: Ruth Kuhn, a hospice patient in Oak Park, gets regular visits from Rosemary Salerno, an Oak Park therapist who works to take the fear factor out of dying.
 JASON GEIL/Staff Photographer

On their living room wall, next to his wife's hospital bed, Jerry Koenig taped up a sign. Her first day back, he says, Marjorie read it aloud six or seven times: "Welcome home, my love."

The decision to bring his wife of 49 years home for her last days was one he and their three adult children made in mid-October.

Marge - who, says Jerry, knew a glioblastoma diagnosis couldn't be beat - had in less than a year been through two operations for her brain tumor, in addition to chemotherapy and radiation treatments. The hope with all these procedures wasn't a cure, but that the quality of her remaining days would improve. When a surgeon suggested one more operation, Marge's family said enough. With the help of a social worker at Seasons Hospice and Palliative Care in Des Plaines, they arranged to bring her back to Oak Park.

At home 12 days later, Marjorie Koenig, 69, was holding hands with her husband and children when she died.

To learn more

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Seasons Hospice and Palliative Care

- 606 Potter Road, Des Plaines
- 847-759-9449
- www.honoringlife-offeringhope.org

Rainbow Hospice and Palliative Care

- 444 N. Northwest Highway, Park Ridge
- 847-685-9900
- www.rainbowhospice.org
- 800-658-8898

Help line for National Hospice and Palliative Care Organization

- www.caringinfo.org

Hospice channel on YouTube

- www.youtube.com/user/NationalHospice



ONE PORTRAIT OF TOGETHERNESS: Marjorie Koenig, shown in a photo held by her husband of 49 years, died at home in Oak Park surrounded by her husband, Jerry, and their three adult children. Jerry Koenig calls the hospice workers they relied on "guides in unexplored territory."

loss and how we grow from it. Hospice gives us a language of dying, a tradition of dying that we've never had in this society. We now have the opportunity to use this experience of death as our path to awakening something bigger within ourselves."

"Hospice," a term that surfaced in this country in the 1960s, at first referred to volunteers checking in on cancer patients. Hospice care in the U.S. is now a multifaceted and multibillion-dollar industry that involves tiers of professionals, includes Medicare funding, and covers all forms of terminal illness.

In a report issued last year by the National Hospice and Palliative Care Organization, 1.45 million people received some form of hospice service in 2008 - a 29 percent jump from 2007. That translates to hospice care for two of every five people who died, and radiates to the people who survived them.

Jerry Koenig calls members of his wife's hospice team "guides in unexplored territory."

"You don't go through this often in your life," Koenig says, "and they do. They know what to expect."

The matters to address in dying well, Salerno says, are three forms of pain: physical, emotional and spiritual.

Tending to pain, thoroughly

Peggi Mizen, a River Forest resident who is a nurse with Rainbow Hospice and Palliative Care in Park Ridge, uses the term "team" to describe how the many caregivers work together.

She says a doctor provides the medical expertise and that nurses and health care aides follow through with, for example, the giving of morphine or other pain killers. Sometimes, complementary caregivers, such as massage therapists, are part of the team.

Finding anxieties and tending to them is the job of the team's social workers. People aren't ready to leave, Salerno says, until they feel sure that the bills are paid, the coffee maker is turned off and someone has promised to feed the cats.

Much of this work is in relationship issues. Salerno gives the example of a dying man who had some reconnecting to do with his adult daughter. He kept asking her to bring his laptop to him in bed. Seeing him so weak, she hesitated but eventually complied.

A family's choice to bring a terminally ill person home to die isn't new. But, as ways to prepare for such reality have evolved, there are newer steps toward order and comfort at home for both the dying person and their survivors.

"It's important for us to recognize that end-of-life care needs to be personalized. ... You only die once," says Diana Wilkie, who holds a doctorate in nursing and teaches at the University of Illinois at Chicago's College of Nursing.

"Dying well" is the phrase that Rosemary Salerno uses for the growing availability and sophistication of home hospice care. Salerno is an Oak Park psychotherapist who has worked in end-of-life care for 18 years. She defines "dying well" by quoting a letter (left) sent to her by a woman in River Forest. In 2004, Salerno had arranged home hospice care for this woman's father.

"You helped my dad end his life with dignity, with freedom from pain, and on his own terms. I was able to witness that and that is what has greatly helped me to cope now."

Salerno, who works with several hospice programs and is also a grief counselor, says that balancing the limits of medical science with attention to emotional and spiritual care makes a difference.

"Death is out of the closet," she says. "So much of our experience as human beings is about how we navigate through

He spent nine hours showing her everything on his computer that she would need to know: how to pay the bills, where the investments were, an inventory of his prized possessions, where those possessions were kept. He so needed to share this information, Salerno said, he found the energy to do it thoroughly.

According to Salerno, spiritual pain often has to do with fear, a kind of spiritual angst. The trouble with fear, she says, is that it can actually generate physical pain. "The main key is getting people out of a fear state. How we do that is completely creative and individualized.

"That's where the chaplain usually comes in."

Rev. Ian Burch, an Oak Park resident and chaplain at Rush Oak Park Hospital, worked for three years as a hospice chaplain. His own father died at home with the help of hospice care. These professional and personal experiences led him to conclude that "as a person gets closer and closer to the exact moment of death, the veil between heaven and earth seems to get much thinner."

The Koenigs' pastor from Grace Lutheran Church, Rev. Bruce Modahl, came to the Koenig home and gave Marge communion. His son, who is a pastor in Algonquin, read Bible passages to her. Members of Grace showed their support by bringing meals. And Marge herself took some responsibility for her spiritual care by asking her two sons and her son-in-law to carry her piano up from the basement, where she had been giving piano lessons. Once she sat down at the piano, she was able to play 30 hymns from memory.

Becoming 'death-literate'

"We have a rabid denial of death in our society," Chaplain Burch says. "From television to ad campaigns, we have a sense that, if we just get the right treatment, we'll live forever. Immortality as an idol is the stumbling block that prevents families from being able to plan ahead for a good death."

Society's fear of broaching the subject of dying prevents us, according to Burch, from becoming "death-literate" and keeps us chained, he says, to an institutional model of end-of-life care. "In our quest to heal the body, we've done something unspeakable to the spirit. There are some things that can't be fixed. And, actually, mortality doesn't need to be fixed. It's simply part of the human condition. We, as a people, are rather bad at seeing that."

Avoidance of anything having to do with death and dying keeps people from planning, Burch notes, even if many say they would like to die at home. Managing details about your death is a can that continuously gets kicked farther down the road.

Wilkie, the nursing school professor, advises that plans be made well in advance of an expected death to ensure that everyone's wishes at the time of death are granted. The federal government tries to make the same point. April 16 is National Healthcare Decision Day, the calendar mark on which people are encouraged to complete living wills.

On Oct. 30, at the Koenig household, both the paperwork and the coaching were in place. Jerry Koenig says the hospice nurse had told him not to call 911 if Marge's death seemed imminent, because paramedics' work is to resuscitate.

"That was probably the toughest thing," Koenig says, referring to signing a do-not-resuscitate form. "Even though we had made out power of attorney documents along with our will in 1992, signing that do-not-resuscitate form was when it really hit."

Charlie Williams of Drechsler Brown & Williams Funeral Home in Oak Park handled the funeral arrangements for Marjorie Koenig.

"Jerry was there in the room when we made the transfer to our stretcher and he was quite comfortable with touching the body and assisting us with the transfer from their bed to our stretcher," Williams says.

"I honestly believe that people who use hospice are more comfortable around the dead. Their loved one has died but the body remains, something sacred. Hospice has allowed families to not only experience the dying process, it has also allowed people to witness the actual death. That makes death less mysterious and frightening."

'I definitely was not scared when my dad actually died'

My dad died ... circled by family about 4:55 p.m. on Monday ...

My daughter, my brother and I were in my dad's bedroom. My daughter was on one side of the bed holding his hand and reciting the rosary. My dad sincerely believed in the power of the rosary. My brother was on the other side holding his hand and intently looking at him. I sat next to my brother, reciting the rosary along with my daughter.

The smell of lavender permeated the room. We had been rubbing it on my dad's hands, face and neck. It had a wonderfully calming effect on all of us.

Around 4:40, my daughter almost yelled, 'It's starting. It's really starting. This is it!' My dad's breathing got a lot more rapid. My dad opened his eyes and looked at us as if to say, 'I'm letting go. It's OK. Don't worry anymore.'

We all felt this atmosphere of calmness. ... all three of us felt a definite leaving of Dad's presence. I felt almost a wind passing over me. I definitely was not scared when my dad actually died.

After we were sure that Dad had actually passed, our first emotional response was one of elation! We had worked as part of a team; we felt victorious in successfully helping my dad pass on to the next stage. Then we allowed ourselves to cry.

Letter by a River Forest woman, to the therapist who arranged hospice care for her dad