



Physical therapists work with Suzanne Waltz in her home. The therapy is designed to ward off stiffness caused by scleroderma.

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# Tidings of comfort

## Hospice focuses on palliative care for the chronically ill.

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**S**uzanne Waltz of Mount Joy checked into the Essa Flory Hospice Center last month. A week later, she went home. Waltz and many other seriously and chronically ill people in Lancaster County are discovering that hospice care is no longer a path toward a death sentence. It's become an inspiration for living. "Hospice gave my life back to me," said Waltz, 59, who suffers from scleroderma, a life-threatening disease in which the body's tissue hardens. Eventually, Waltz's lungs will grow stiff, and she will die. But until then, Waltz plans to live her life to its fullest. "I want to spend time with my children," said Waltz, who plans to fly to Seattle to visit her daughter for Christmas, something she could not have imagined doing just two months ago.

"Hospice has evolved," said Janet Carroll, vice president of clinical services for Hospice of Lancaster County, 685 Good Drive.

Hospice is not merely a place, she said. "It's become a philosophy of care."

That philosophy is far-reaching; it's changing the way doctors, nurses and other healthcare givers view and treat people diagnosed with terminal illnesses. It's created a whole new method of care for those with chronic illnesses. It also has a new name: palliative care.

The word palliative is derived from the Latin "pall,"



Thanks to the palliative care she receives through Hospice of Lancaster County, Suzanne Waltz can be at home — with her ceramics, and with all the other furnishings that make her life familiar and comfortable.

which means to cover, typically the black cloth that covered a casket. (Hence, pallbearer.)

Today, however, it means "cover with comfort," said Tim Nickel, a pastoral therapist, at Masonic Village in Elizabethtown. (Thanatology is the study of death.)

The emergence of palliative care has led caregivers to understand and accept that, along with fighting an illness to the bitter end, it is important to use every means available to help the patient live as full a life as possible up to death.

That's how Waltz wants to live.

### Pain like no other

Until she discovered all that hospice has to offer, she was as good as dead, she said.

The pain from her illness was so overwhelming, she could not get out of a chair. She could not be a mother to her children; she could not be a wife; she could not work or indulge in her hobbies of sewing and painting ceramics.

"I thought I knew pain, but I've learned there are all types of pain," said Waltz.

Pain is energy-consuming, said Dr. Joan Harrold, medical director at Hospice of Lancaster. It creates fatigue, emotional anxiety and mental depression.

But some pain medications make patients tired or weak. Finding the balance between pain relief and tiredness requires continual adjustment, she said.

"In hospice, we are very clearly working with symptom management," said Harrold. "We offer a supportive presence."

Waltz remembers when Hospice of Lancaster County invited her to stay at the facility where she could get help with fine-tuning her medications.

At that time, the only thing Waltz knew of the hospice center is "this is where people go to die."

As time passed, however, she began to understand that the hospice's goal was to send her home in better shape than when she came in.

She stayed for seven days.

Today, said Waltz, she is pain-free.

Hospice also sends two nurses to her home to help her continue to manage her medications and to provide other personal care. Through Waltz's Medicare coverage, the center also sends a rehabilitation specialist to teach Waltz

Please see HOSPICE, page 04

# Hospice: For living

Continued from G1

therapeutic hand and arm exercises that will ward off the paralyzing stiffness caused by scleroderma.

Hospice helps seriously ill people and their families understand the difference between "getting better and feeling better," said Carroll. At times, through palliative care, it's possible to have it all.

## Never walk alone

The compassion that Hospice has long practiced with seriously ill people and their loved ones has become contagious in the past 10 years.

"Many terminally ill people die in a hospital," said Harrold. "Hospitals began to say, 'We have to do a better job' at end-of-life care. Hospice said, 'We can help you.'"

Dr. Ken Brubaker, of Geriatric Associates at Lancaster General, said because of hospice's influence, "end-of-life" care is moving toward a "symptom-management model."

"What's unfortunate in Western medicine," said Brubaker, "is doctors are taught to treat the illness. We tend to deny death 'til the very end."

"People who are dealing with a terminal illness need a doctor who will be upfront with them. 'We can't cure this illness, but I will walk with you through life as we deal with the end coming.'"

One patient who received a terminal diagnosis, for example, sought out another specialist who promised her two to three more "good" years, Brubaker said.

Believing it was possible to live as if she were not ill, the patient would go to the emergency room every time a symptom would arise, as if it were something new and shocking.

At one point, said Brubaker, the woman fell in a parking lot. "She decided to come see me instead of going to the ER."

"She realized she was dying and she needed to change course," he said. She did, indeed, have two to three more years, but without palliative care, those years would not have been "good."

"Hospice is a real blessing, and doctors are beginning to see a necessary role for hospice earlier on," he said. "It's no longer strictly end-of-life care; it's helping people move down the continuum."

## New specialty

Along with the integration of hospice philosophy in the traditional health care setting, the industry is beginning to see doctors, nurses and other providers specializing in palliative care.

Tim Nickel at Masonic Village has lived the trend.

Nickel's career evolved over the past 20 years. After earning a bachelor's degree in psychology, Nickel became a nurses' aide at Masonic Village. In his first eight months on the job, 12 of his patients died.

Trying to come to terms with the issue of dying, Nickel switched to the housekeeping department. During that time, he earned a master's degree in thanatology at Hood College, Frederick, Md.

In 1999, he helped form a death and dying committee at Masonic Village, which explored the myths, perceptions and cultural responses to death.

Since then, the retirement community's end-of-life pro-



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Licensed practical nurse Susie Reich is one of the Hospice caregivers who assists Suzanne Waltz.

gram has been transformed, said Nickel.

Alzheimer's disease and other forms of dementia have played a key role in changing the dynamic of dying.

"We're not sure when people with dementia are going to die," said Nickel. "It could be two weeks, it could be two years."

Used to be, hospice care was provided at the last stage of life, but today it starts with the medical diagnosis. "Hospice care or palliative care has shifted from just months to live to years to live," he said.

## Sense of loss

Eleanor L. Wolf of Mount Joy was by her husband's side last spring when he died in the dementia unit at Masonic Village.

Richard W. Wolf Sr., a former high school track coach and assistant principal, went peacefully and with dignity because of the

"protection" and comfort the unit workers provided, said his wife.

During his two-year stay in the unit, which caregivers call a "neighborhood," Richard Wolf was able to live like he did at home. "He was so well-protected," said his wife Eleanor, who spent five to six hours a day with her husband.

She said he started to go downhill last Christmas.

An average of 250 people a year die at Masonic Village, but Nickel and others on staff have learned that "at the time a resident comes here, the sense of loss has started.

"They've left their home; they may have lost a spouse ...," he said.

At Masonic Village, the hospice area has 40 to 50 patients at a time. Six years ago, said Nickel, that average was 10. Hospice of Lancaster County treated an average of 200 people a year. Today the average is 400.

"It's just fantastic, the steps we have taken in six years," he said. "It's introduced a whole other level of care."

And, said Nickel, "just putting it out there for everyone to talk about" has brought Nickel closer to his goal — to create for residents and their families a sacredness about life ... and about death.

## FYI

To learn more about palliative care contact:

• Hospice of Lancaster County, 685 Good Drive.

Phone: 295-3900

• Tim Nickel and the Rev. A. Preston Van Dourson, Masonic Village at Elizabethtown, One Masonic Drive, Elizabethtown.

Phone: 367-1121

• National Hospice and Palliative Care Organization, 1700 Diagonal Road, Suite 625, Alexandria, VA 22314. Phone: (703) 837-3139.

Web site: [www.nhpco.org](http://www.nhpco.org)