



FOR: Hospice & Palliative Care of Northeastern Illinois
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FOR IMMEDIATE RELEASE

PIONEERING VISION PLANTS SEEDS FOR HOSPICE

*From Modest Beginnings, Hospice & Palliative Care of
Northeastern Illinois Serves Six Counties*

When a small group of Barrington IL residents gathered in Dave and Carol Nelson's home 26 years ago, they shared an overriding common thought: if the volunteer hospice movement has gained such acceptance in England, why not here?

Some of the group had learned about hospice from witnessing it personally. Carol Nelson recalls how, back then, oncologist Dr. Larry Kilton and his wife Sharon, a nurse, would come to visit her good friend and neighbor who was dying of cancer. "They'd come to his house every day to give him pain relief and comfort," she recalls.

Others, like Freddie Pederson, learned of it through reading articles and books. "I always thought this was a wonderful way to help your neighbors," she says. "I also thought, 'Oh, there'll never be anything like that here.'"

Others knew of it from travels to the UK. Roxy Pepper, who was later approached by Pederson to help support the group financially, recalls having her curiosity piqued by the concept of hospice when visiting England.

HOSPICE BACKGROUNDER/Add One

What none of them could know, or even guess, was that they would be instrumental in creating the organization — now called Hospice & Palliative Care of Northeastern Illinois — which would become one of the largest nonprofit hospices in the region. With an annual operating budget of \$16.5 million, staff of 150 and over 300 patient-trained volunteers, today the organization founded by a group of committed volunteers and their friends reaches 1,454 patients a year in six counties.

It was Dr. Kilton who approached Dave Nelson, a Barrington community leader and Village Board President, about bringing together a group of folks who had demonstrated community leadership and who would take on a cause with passion if they thought it was the right thing to do. He wanted them to hear about hospice and the difference it can make. He had with him Dr. Elizabeth Pannier, PhD, a psychologist who had also been providing hospice care.

Kilton and Pannier explained that “hospice,” from the Latin *hospitium* or guesthouse, describes a place where weary and sick pilgrims could find shelter and rest in medieval times. In the modern hospice movement, the shelter is generally not a physical place, but rather a concept of care.

“We could see there was a void in the community,” says Dave Nelson. “We saw right away that an organized hospice was something more than just for our community — it would be a resource for the entire region.”

After a series of meetings — “Carol’s famous chocolate chip cookies were a huge draw,” says Dave Nelson — the group decided, “We can do it if we really get behind it.” Drawing on that can-do spirit, a one-room office was set up with just a desk and a phone. They called their not-for-profit program Hospice of Northeastern Illinois (HNI).

The core group of about 20 helped with financial support, logistics, volunteering, leadership and everything it took to make the idea succeed. Among these, in addition to Kilton and Pannier, were Roxy Pepper, Freddie Pederson, Bruce Carlson, Sam Oliver, Steve Mountsier

HOSPICE BACKGROUNDER/Add Two

and the Nelsons. They began the process of applying for non-profit status, raising funds and awareness, creating volunteer trainings and materials, and developing a Board.

Freddie Pederson remembers going to the little office to answer the phone: "It was all about neighbors helping neighbors at the most difficult part of life. We were all volunteers. Even the nurse was a volunteer." She took the six-week training class that was offered and visited patients in their homes. "I had a gentleman — I would go to his house so his wife could have a little break. I was like a sounding board for him and his family," she says. "Then I did bereavement with his wife. We became good friends."

They followed the multidisciplinary approach that Cicely Saunders had laid out in England in founding the hospice movement there, according to Pannier. They sought to attract volunteers from all the disciplines: nurse and nurse's assistant, social worker, chaplain, and volunteer.

"We tried our hand with a couple of patients back in 1985," recalls Pannier. One was a young man with ALS, and the other was an infant suffering from a neurological wasting disease that had already claimed some siblings. "We almost didn't take that one," she says. But they did, and provided shifts around the clock. "We not only helped the child, but also the parents and several siblings who weren't sick."

Soon the demands outstripped the tiny space, and larger premises were needed. Financial support from a number of interested community members led to larger offices, first at Good Shepherd Hospital and then on Hager Avenue. A Board was officially formed, and many of the original founders sat on it, including Pederson, Kilton and Pannier.

The nascent organization continued to grow. Initially a volunteer hospice, it became licensed as a full hospice in 1988, with a director and clinical staff. They earned Medicare-certified status the following year, and Hospice of McHenry County then merged into HNI, thereby extending its history by another couple of years — back to 1982, when five Woodstock women pooled their resources to offer end-of-life care in far northeast Illinois.

HOSPICE BACKGROUNDER/Add Three

Other mergers, including Northwest Community Hospital's hospice program, further extended the program's reach into the surrounding communities. Additional workstations and geographical teams were set up to better service the expanded area.

Over the years, HNI added the Joint Commission Gold Seal of Approval to its full accreditations, and its approval ratings remain consistently impressive, with 98% of referring physicians and 100% of referring hospitals rating the quality of service as very good or excellent. Most significantly, 96% of family members said they would recommend the agency to others (Deyta, 2009).

The group came up with the idea of forming a separate Foundation to support the hospice in 1992. "We needed to raise money for people who need something extra that's not under benefits," Pederson explains. Some services, such as Camp Courage, the innovative grief-support summer camp program for children who have experienced loss — are subsidized by Foundation funds.

She remembers the time a young man who had been helped by Camp Courage attended a Board meeting to sing a song he'd written about a person in his family who'd died. "You can be sure there was not a dry eye," Pederson says.

Even if a patient is subsidized by Medicare or Medicaid, there are services that may not be covered, like massage, and art and music therapy. "It's always been our core value as a not-for-profit that the patient's needs as an individual come first," she declares. "We've never turned anyone away for inability to pay." Last year, the Foundation subsidized almost \$600,000 in unfunded costs, according to Pederson, who has sat on the Foundation Board since its inception and is its Honorary Chairperson.

By 2002, HNI had served its 10,000th patient. In 2004, over 1,300 patients received hospice care, more than 2,000 accepted bereavement services, and the hospice Foundation raised more than \$1.5 million in donations.

HOSPICE BACKGROUNDER/Add Four

These totals have continued to escalate today, with over 20,000 patients receiving care since the organization's founding, and 55,000 taking advantage of bereavement services in the past 10 years.

Meantime, HNI put its toe into the water of Pediatric palliative care with the launch in 2005 of Hope's Friends. It became one of very few hospices to use its expertise specifically to provide pain and symptomatic relief for children with serious chronic illness, establishing close relationships with Children's Memorial and Lutheran General Hospitals, among others.

"Our pediatric palliative program has gone beautifully," Pederson enthuses. She points out that there are not many of these hospices nearby, as you need special nurses, special training, and for a hospice to undertake such a project is costly.

The success of the pediatric program, along with recognition by the AMA of palliative medicine as an official Internal Medicine subspecialty, led to the recent expansion of HNI palliative care services into the greater community. The goal: To help people with chronic or acute, but not necessarily life-limiting, diseases feel better by managing pain and symptoms, emphasizing nutrition, and providing assistance in daily living.

Offering palliative care also helps take away some of the fear and misunderstanding surrounding hospice, Pederson believes. "A lot of people think if you say the word hospice, they are dying," she says. "Palliative care gives us another way to serve people. They may or may not ever need hospice services, but I would hope it brings people to a better understanding of hospice."

The hospice also recognized that to fulfill its commitment to reach every person who can benefit from hospice care, the reality that not all terminal patients' symptoms can be managed at home had to be addressed. Sometimes a patient needs 24-hour care and the family just can't provide it. Or the family caregiver needs a break, or maybe needs to get away for a few days or a week.

Rooms at Centegra Health Systems had been used from time to time as hospice rooms, so

HOSPICE BACKGROUNDER/Add Five

the organization was receptive when HNI approached Centegra Health Systems about the possibility of creating an inpatient unit specifically for hospice patients in Woodstock. HNI worked closely with Centegra Health Systems to design and build a first-rate inpatient unit at the hospital. The 10-bed unit opened in 2007.

Still, that inpatient unit wasn't the fulfillment of the founders' dream, according to Pederson. For years, the founders had spoken of having a freestanding hospice home that would really feel like home.

For some people, it's so difficult having their loved ones at home, and they don't have support from family or community, she explains. Pederson herself had been inspired by a visit to a hospice home that was serene, with rooms you could leave to go into a garden. "We could do that here," she thought.

In 2007, recognizing the mounting needs of aging communities in the six counties region, the Hospice and Foundation Boards decided to make the dream of a hospice home a reality after a feasibility study confirmed a great call for such an offering. They launched an \$18.5 million capital campaign to build the first "green" hospice in the state of Illinois.

Generous support from Board and community members permitted ground to be broken in Barrington for the Pepper Family Hospice Home and Center for Care, a freestanding 16-bed in-patient home and headquarters for Hospice & Palliative Care of Northeastern Illinois (the name was changed in 2009 to recognize HNI's expanded palliative care services). The Pepper Family Hospice Home will open its doors July 1, 2010.

Carol Nelson, who now sits on the Foundation Board, wishes it had been there for her father, who passed away from bladder cancer a few years ago, and who could not stay at home for pain management reasons. "I've driven by it and walked through it and thought, 'what a wonderful place to die.' If you can't be home, this is the next best thing."

Now that the community fundraising phase is nearly over, she plans to get involved with Hospice & Palliative Care of Northeastern Illinois's next phase: community information. She -

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says there's lots of misinformation out there about hospice, and about palliative care as well.

Echoing the determination of the founders, she declares, "Once the home is built, we'll go into the community and talk about it, and about what we do. Education takes away fear of the unknown. After all, it's about the quality of life until the last breath. Why not make every moment you are still alive the best it can be?"

About Hospice & Palliative Care of Northeastern Illinois

Hospice & Palliative Care of Northeastern Illinois is a not-for-profit organization serving families throughout McHenry, Lake, Northwest Cook, Kane, Boone and DuPage counties. Founded in 1982, the agency provides comprehensive end-of-life care to over 1,400 patient families each year. The organization's palliative care program offers services for those who struggle with serious illnesses as well as pain and symptom management. Hospice & Palliative Care of Northeastern Illinois is Medicare certified and accredited by the Joint Commission. For further information, please visit www.HospiceAnswers.org and www.PepperFamilyHospiceHome.org.

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