



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

LIVING, NOT DYING, IS FOCUS OF END OF LIFE CARE

Hospice Nurses Recount Gifts of Helping Patients & Families

Being a hospice nurse is a calling. It's not just something you wake up and decide to do one day. It's an inner motivation.

That's what Eileen Grace, RN, CHPN, Chief Nursing Officer at Hospice & Palliative Care of Northeastern Illinois says. And she would know. She's been providing end-of-life care for over 25 years. Grace joined HPNI, one of the largest not-for-profit hospices in the region, a little over two years ago. Before that, she did provide hospice care in a variety of settings and roles.

As a new oncology nurse, she had been frustrated because she thought existing health care centers were not well equipped to meet the needs of those dying. "At that time, there were no hospices to refer to," she recalls. "I was very drawn to care that would make patients and their families more comfortable at end of life." So moving into hospice work was a natural transition.

The story is repeated by Daneen Gorski-Adams, RN, OCN, CHPN, who is Associate Director of Inpatient Services at HPNI. "I came here more than four years ago after personal experience with end of life," she says. Until then, she had been an oncology nurse, guiding people to the support of hospice. "It's not the type of work you just do," she says. "If you don't feel it in your heart, you don't belong here."

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HOSPICE NURSES/Add One

Both agree that hospice care is one of the best-kept secrets, and are determined to get the word out about what hospice does. Here's what they want you to know:

- Hospice services are covered by Medicare and most insurance. It's available when you have a diagnosis of six months or less to live but if you live longer you can continue to receive hospice care. Unfortunately, most people only take advantage of about three week's worth of this six-month benefit, if that.
- Your personal physician remains in charge of your care if that's your desire. Your hospice team consults with him or her on an ongoing basis.
- The care plan is entirely personalized and focuses on patient and family goals, based on home visits by your interdisciplinary care team (nursing, medical, social work, spiritual, home health aid, integrative therapies and volunteer services) with you and your family. It reflects your choices about your personal goals and how much control you want to exercise over your care.
- Your team members visit you at your home or place of residence, and the entire team meets to talk specifically about your care needs at least every two weeks, and consults with your doctor about any proposed changes. Integrative therapies including massage, art, Reiki, pet and music, are also offered.
- Hospice care teams are experts at managing end-of-life symptoms and pain, so you can live your final days to the fullest with dignity. It also excels in providing other comfort, both spiritual and emotional, and supporting fulfillment of "final goals" of patient and family.
- Care is available to manage pain or symptoms when these cannot be managed comfortably at home. HPNI operates a ten-bed inpatient unit at Centegra Hospital in Woodstock and will be opening a freestanding 16-bed hospice home in Barrington this summer.
- Patients' families are able to receive 13 months of grief support.

One of Gorski-Adams's favorite stories that demonstrates the lengths to which HPNI will go for its patients was the time the pediatric team was caring for a 12-year-old boy who lived in a private home with his mother and 3-year-old sister. The young man had a brain tumor and a tremendous amount of pain. Together the pediatric social worker and the inpatient social worker met with the patient's mother, and they explained the role of the inpatient unit, the benefit of having around the clock nursing care, and the ability for the mother and sister to stay with the patient.

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HOSPICE NURSES/Add Two

The young man was given a room at the Woodstock inpatient unit with an extra large bed, allowing his mother to hold him as he slept. The social worker spent a lot of time with the mother, and the final decision was made for comfort care. "His mom wanted to be sure he had any pain relief he needed, and we put them both together in a large bed where they could be comfortable," recounts Gorski-Adams. She takes a breath and continues, "He died while sleeping in her arms."

When the young man passed away, the family did not have funeral arrangements in place, nor did they have the financial support for a funeral ceremony or burial. The social worker was able to work with members from HPNI's community resources and was able to get services donated by one of the local funeral agencies.

Sometimes the personal goal articulated by a patient can be physical: "I don't want to die in pain." "I'm afraid I won't be able to breathe." Other times it can be emotional: "I haven't talked to my sons for years. I need to do that." Or a last journey: "I want to go on a fishing trip" or "I want to visit my grandkids in Minnesota."

Articulating these goals and then trying to fulfill them is incredibly healing, says Eileen Grace. One of her patients, who'd been estranged from her daughters due to her alcohol abuse when they were growing up, felt badly about that part of her life. She decided she wanted to take them to Disneyworld even though they were adults by then. "We were able to get donations and send her and her daughters to Disneyworld," says Grace. "It was extremely healing — it meant everything to that family." Gorski-Adams agrees, adding, "It's all about what the individual needs. No two of us have the same end of life experience."

"We're great at managing symptoms, but it's the other, personal things we do to enhance the patient's quality of life and that of their family," says Eileen Grace. "That's what hospice is really about. We get letters every day saying, 'I never could have gotten through this without you.' "

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HOSPICE NURSES/Add Three

She continues, "I know how scary embarking on that journey can be. We don't want to think about it. We don't want to talk about it. But we all die." She says that although they struggle with how to get people to see what a great support hospice can offer the patient and family, "once the family has gone through it, the next time they call much earlier."

She points out that other things hospice does are less dramatic but still important. The patient is supported in doing a "life review," a therapeutic process that allows you as the dying person and your loved ones to appreciate who you are, what you've achieved, and the legacy you're leaving. Or a volunteer comes over to relieve your caregiver so she can take a much-needed break.

Speaking of her own experience with hospice, Grace says that she has learned the lessons of impermanence and forgiveness. "The one thing I've learned is we never know when it's going to be our time. We care for people from infants to their 100's. Every day is a gift, and so you don't get caught up in things that are unimportant." She adds, "It's all about relationships — being a father, a friend." She thinks that's why people do hospice work — it reminds them every day of what's important, and to appreciate every day.

She says there's a lot of peace in knowing that nothing is permanent, and even if you're going through a hard time, it will pass. That's helped her with learning not to have unfinished business down the road. "Maybe I need to tell someone how much I love them, or apologize." Recently, she was able to have a healing conversation with her father, who has been diagnosed with bladder cancer and has challenges in expressing emotion. "Hospice workers witness miracles of families coming together and emotional wounds are healed every day," Grace conveys.

Grace and Gorski-Adams are hoping that the soon to be opened Pepper Family Hospice Home and Center for Care will help de-mystify hospice. They see it as a place the community can come and be exposed to hospice in a different, less threatening way. Dying used to be part of everyday life supported by the community, they point out. Now, the

experience is institutionalized, and we need to bring the community back into it. They believe the physical building does that.

HOSPICE NURSES/Add Four

Sometimes people might want to help out and aren't sure how. They suggest volunteering to read to a patient, or listen to their stories. Or you can bring in your skills and gifts such as preparing a meal for a family or baking cookies, doing a craft project with them or gardening.

The public is invited to use the home for meetings, to relax in the library or family room, to find serenity in the meditation room and gardens. "It takes a community to raise a hospice," says Gorski-Adams. "That's the only way we can remove the secrecy or stigma and give back to those who have supported us as we've grown."

"It's a rich time in people's lives," says Grace. "It's a gift to be part of it. It brings us back to what matters, what's real." Adds Gorski-Adams, "When you go home at night and you know you've made a difference, it's a really good feeling."

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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