

The Circle of Life

Families Find Strength Through Hospice Care

By Autumn Rhea Carpenter

Rockford native Dave Hopp thrived during an era of shiny cars, spotless service stations and community pride. For 30 years, the gregarious man welcomed customers into his meticulously-maintained Rural Oaks service station. He married his true love, fathered three girls, was a loyal member of Shriners of North America and was known for his charisma.

Three years ago, after seven years of battling stroke and heart problems, Hopp died in his home surrounded by his family members. During the last month of life, the beloved husband, father and friend chose hospice care. That decision brought Hopp dignity, control and an end-of-life experience that his family still praises today.

Hopp's eldest daughter, Cindy Jensen, of Rockford, learned about Northern Illinois Hospice and Grief Center during the 1980s when she owned a balloon delivery business.

She formed friendships with staff members and developed a respect for the center and its work. The last time her father was placed in P.A. Peterson Center for Health, Jensen, with her two sisters and mother, agreed that it was time for hospice care—an environment in which pain is managed and the patient is surrounded by loved ones during the last stage of life.

“We all knew how sick he was, but to hear the words ‘hospice care’ was shocking,” recalls Jensen. “It made the entire experience real.” The family chose Northern Illinois Hospice and Grief Center, which was founded in 1979 as the first hospice in northern Illinois. Dating back to medieval times, the concept of hospice symbolizes a place where travelers, pilgrims, the sick, wounded or dying could find rest and comfort.

In nearly 30 years, the center, sometimes called the “mother hospice,” has educated the public on important end-

of-life options, specifically designed for those with a prognosis of six months or less, says Fleur Wright, director of public support. The center provides patients, ranging in age from newborns to those in their 90s, with personalized care in their homes, nursing homes and hospital rooms. Hospices provide various levels of care that are tailored to each patient's needs.

"A team is assigned to the patient and family," explains Wright. "Initially we train the caregiver on procedures, such as preparing a certain type of food or regulating oxygen. Our certified nursing assistants (CNA) can provide personal hygiene services, such as bathing and helping men to shave—whatever makes them feel physically better. We also offer necessary light housekeeping services, emotional support and necessary medical supplies." Northern Illinois Hospice and Grief Center staff includes 38 team members and 70 active volunteers.

Niceta Cover, nurse manager at the OSF Hospice, Rockford, Ill., explains the specific skills required of hospice nurses. "Nurses should have a solid background in medical surgical nursing, and it's beneficial to have at least two years of home health care experience and effective pain management techniques," she says. "Our nurses understand that the period of aggressive treatment has ended. They concentrate solely on making the patient comfortable."

Hospice teams are comprised of nurses, trained volunteers, hospice physicians, social workers, chaplains and spiritual guidance counselors, bereavement service providers, a medical director, patients' personal physicians and speech therapists, physical therapists and occupational therapists. OSF Hospice employs 16 staff members and has about 30 active volunteers.

"Each volunteer performs valuable duties. Our direct care volunteers are trained to assist caregivers," says Wright. "They perform errands or simply remain present with the patient. Friendships often bloom that might not happen elsewhere."

Research is paramount when seeking hospice care. Important questions to ask include: How does the facility assure that each patient's treatment remains confidential? Is 24-hour assistance available? Does the hospice maintain a list of references, such as doctors, patients, and family members willing to share their perspectives? Will the hospice create a care plan?

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"It's very important to gauge the staff members' various competency levels and to determine their education and experience," says Cover. "Other important issues include procedures for monitoring medication, payment and availability. It's vital that the patient find a hospice that matches his or her own philosophy because it's such a personal experience."

Preparing important paperwork is another step of entering hospice care.

"When a patient first receives life-limiting news, he or she should start preparing an advance directive that authorizes a specific person to make important decisions," says Cover. "Dealing with an illness is stressful enough, without worrying about administrative details."

"The social worker also asks whether the patient or family members require certain social services and helps to attain them," says Wright. "The social worker asks if there is a specific goal that the patient would like to accomplish during his or her final months. Often they are simple requests, like riding in a hot air balloon or living until a granddaughter's wedding. We strive to make these important wishes happen, in order to give patients resolution."

Hospice benefit is available through Medicare and Medicaid. Most private health insurance companies also include a hospice care benefit. Neither OSF Hospice nor Northern Illinois Hospice and Grief Center will deny service because of an inability to pay.

Both centers offer bereavement services that allow staff and family members to talk about the deceased patients and deal with loss in a healthy manner.

"We are at the service of these families for at least a year after the patient dies," says Wright. "Contrary to



Niceta Cover

popular belief, this is not a depressing place to work. There are certainly sad stories, but our work to fulfill last wishes gives us tremendous strength and creates an equal balance.”

Besides the many funerals over which he presides, the OSF Hospice Chaplain “recently had the honor of presiding over a wedding for one of our patients and his companion,” recalls Cover. “Staff attended the wedding, took pictures and celebrated a small reception for the newlyweds, who are both in their 80’s. It was a sweet day and affirms that Hospice is about life.”

Both organizations work hard to educate the public, since many misconceptions about hospice persist. “Many people think that hospice patients suffer only from cancer,” says Cover. “It’s one of the more prevalent diseases that we see, but there are many others, including ALS, AIDS, Alzheimer’s, comas and diseases related to the heart, liver, kidney and lungs.”

Misunderstandings also exist about the timing of hospice care.

“We need to get medical referrals sooner so that people are not receiving our services only a few days or hours prior to death,” says Cover. “Often people think that they are not allowed to see their medical physician once

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Americans’ attitudes toward death often contribute to these misconceptions.

“Our culture still hides behind euphemisms when it comes to death,” says Wright. “We tell children that

grandpa has ‘gone to sleep,’ instead of clearly explaining death. This only confuses kids, sometimes making them afraid to go to sleep. Talking candidly about death as a part of the entire life cycle removes the mystique and makes it less scary. We explain that dying can be an opportunity for the family to share positive experiences, rather than only sadness, pain and loss. Our goal is to empower people to cherish the final chapters of their lives.”

In addition to receiving outside support, patients can continue living normal lives. “Our volunteers recently organized a 75th birthday party for a patient and invited all of her friends and family,” says Wright. “It was such a big way to celebrate her life.”

During the last few weeks of Hopp’s life, his family was able to form strong bonds by swapping stories and exchanging formal goodbyes. Northern Illinois Hospice and Grief Center staff members, Kellie and Pam, provided constant care and reassurance to the family, says Jensen. “Dad adored Pam,” she says.

“They joked that they should run away together. His face lit up when he saw her—it was amazing to receive that level of professional care delivered with such love.”

The home health care experience allowed the family to reconnect, sometimes reverting to childhood giddiness. “The night before Dad died, we laughed all night and mom kept telling us to be quiet. It was the first time in many years that my sisters and parents were all together under the same roof,” says Jensen. “That’s a memory I cherish because it wouldn’t have happened if Dad had been stuck in a hospital room.”

The day Hopp died, his family spent hours playing the dominoes game called Mexican Train. “We left to get Maid-Rite chocolate malts; during that time, Dad died,” recalls Jensen. “When we returned, I cannot explain the sense of overwhelming joy I felt. I knew that his spirit was in Heaven, no longer suffering. We walked outside and witnessed a double rainbow, with the clouds shining through. (We called them God lights.) The entire experience left me with an incredible peace. Without question, I recommend hospice care. I cannot imagine someone dying without it.” ■



Fleur Wright