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## **HOSPICE PROGRAMS ENHANCE QUALITY OF LIFE**

*Hospice & Palliative Care of Northeastern Illinois  
Expands Offerings, Community Outreach*

There's a lot of confusion out there around end of life care, as seen most recently in the factious health care debate. "Death panels, mandatory euthanasia counseling, death books for veterans -- so many myths!" sighs Siobhan White, who's Director of Programs for Hospice & Palliative Care of Northeastern Illinois, one of the largest nonprofit hospice provider in the six county region.

'What people don't realize, unless they or someone they know has actually experienced hospice care, is that it's all about living, not dying," she says.

It's easy to understand her frustration. After all, the organization has been providing services to the region since 1982.

Take the case of one of her organization's patients, Sam, a recovering drug addict who was estranged from his family. When he became very sick at age 41, he was administered Last Rites in accordance with his faith and then referred by the hospital staff to hospice care. Unfamiliar with hospice, Sam was initially hesitant. According to his sister Christine, hospice

managed his pain, gave him back his dignity, and helped Sam re-establish his relationship with his son, who was serving in Iraq, and with her. Speaking of his hospice social worker who visited him several times a week, she says, "She brought comfort and peace to him when he was afraid." Hospice also helped with "mounds" of paperwork and advocated for his rights as a patient.

"We needed that time as a family," she says. "At first, you think of hospice last, that it is the end. But for us, it was a beginning, a healing. I thank God for that."

Sam's story is repeated over and over, and in patients of all ages. As the saying goes, time is our most precious commodity. And the quality of that time is enhanced when we are free from pain and symptoms.

White and her colleagues at Hospice & Palliative Care of Northeastern Illinois are determined to find ways to demystify and de-stigmatize the concept of hospice by getting the information out to the community about what they do.

"People don't like to think about dying," explains Cindy Muskatow, President and CEO of Hospice & Palliative Care of Northeastern Illinois, "or even talk about it, especially in our culture which is focused on preserving life at all cost." She points out that hospice is not about either prolonging life or hastening death, but about providing specialized knowledge of medical care, including pain management, to improve the quality of one's last days.

A wide variety of programs are offered by the organization in support of its central mission of providing personalized, top quality **adult and pediatric hospice care**, delivered primarily in the patient's home or the places they call home, such as assisted living or nursing homes.

- Annually over 1,450 patients receive **comprehensive end of life treatment** from a staff that is expert in care coordination, and pain and symptom management. Nurses, physicians, integrative therapists, spiritual counselors and other staff, plus trained volunteers provide a multidisciplinary team approach.

- White points out that **pain management**, hospice's specialty, is key: "It's so hard to relax and enjoy spending time with your family when you're in pain." She adds that once you address the pain, all your other goals fall into place.
- A spectrum of **integrative therapies** are available to the patient and his or her family to promote their comfort and security. These include art, music, massage and Reiki therapy, as well as pet visits.

"Massage is great for stress and pain relief, while music is soothing and encourages life reminiscences," says White, adding that art therapists often work with patients to address end of life goals. With children — whether patients or family members — art therapy helps release emotions around end of life issues.

- **Volunteer support** — by over 300 trained volunteers — provides all manner of care to patients in their homes, including light housekeeping, relief allowing family members to step out and do errands or just have a break, socialization and companionship, and bedside vigil to support the organization's commitment that none of its patients will die alone.
- A vibrant outreach program to the **Latino community**, which started in 2008 with a grant in partnership with Northwestern University to examine that community's attitude towards hospice care, has added a Spanish speaking physician and bilingual social worker as hospice resources.
- On occasion, a patient's symptoms may not be manageable at home. In such a case, the organization offers a ten-bed **inpatient unit** at Centegra Specialty Hospital in Woodstock. "Its purpose is to manage acute symptoms and ease the burden that families experience when caring for a loved one with a terminal disease," White explains.

A state-of-the-art freestanding **hospice home**, the Pepper Family Hospice Home and Center for Care, is in the process of construction by the organization. Slated to open July 1<sup>st</sup>, it will provide 16 additional private patient rooms in a beautiful wooded and healing gardens environment in Barrington.

- **Veteran's care** is one of the hospice's specialties. Staff has been trained to address this population's special needs, including higher occurrences of cancers due to exposure to Agent Orange and symptoms relating to PTSD (Post Traumatic Stress Disorder). Hospice & Palliative Care of Northeastern Illinois also sponsors Servicemen's Clubs in nursing homes in several of the communities it serves. The clubs, which feature speakers on topics of interest to them, are run by the residents with the help of a hospice volunteer.

“We are also participating in the Library of Congress veteran history project for memorializing WWII stories, ” says White. “We also document these stories for the families to have.”

With its emphasis on a personalized, holistic approach to providing care that enhances one’s quality of life and optimizes the time spent with one’s loved ones, it’s no surprise that supporting the family through its **grieving process** is a core mission.

- At the Hospice & Palliative Care of Northwestern Illinois’ Center for Care, **bereavement support services** are provided free of charge to families of patients who have died in hospice. These services include grief education and support by phone, mail and Internet communication. Open grief groups, community-based memorial services, and comprehensive grief assessments by licensed counselors also are available without fee. Individual grief counseling services and loss specific groups are offered on a sliding scale basis although no fee services will continue to be provided in cases of financial need. Over the past 10 years, 55,000 people have received support from the bereavement program.
- Children who have experienced the death of a family member also can receive support services, without charge, through the Center. **Remember U** is a professionally led monthly support group for children, teens and adults who meet for peer support and education throughout the school year. **Camp Courage, a 4-day summer camp**, is held each summer to provide more intensive grief support and education to children ages 6 – 13 in a safe, caring and fun-filled environment.
- The Center for Care also offers palliative care, integrative/complimentary therapy and bereavement support services to the communities it serves. Individuals who are not members of a hospice family may access open groups, grief assessments and phone consultations, without charge. Individual grief counseling and loss-specific group services are provided on a fee basis except in cases of financial needs. **Community support** by licensed counselors and social workers also is available in response to community need and traumatic or tragic loss.

Other programs reflect the expanded reach of the organization into **palliative care**, where the staff’s expertise in pain and symptom management is provided to patients with serious conditions such as diabetes, cancer, congestive heart failure, lung and kidney disease, or dementia, in consultation with the patient’s medical provider.

- The goal of **Hope's Friends** — one of the few **pediatric programs in the state that provides hospice and palliative care** — is to help young patients with advanced or life-limiting diseases and their families live every day as fully as possible while remaining in their home environment.

"Our pediatric team works together with the child and family and the child's physician to develop an individualized plan of care to meet each child's unique needs," says White of the innovative program. "Some children may be in our program for many years while seeking a cure."

The program also serves 10 patients at the Marklund Philip Center for Children in Bloomingdale and works closely with Children's Memorial and Lutheran General Hospitals.

- The **adult palliative care program**, launched the community last year, has proved very popular. The organization's advance practice nurse works in consultation with the patient's physician, providing relief from symptoms such as pain and side effects from aggressive treatment. It helps keep patients out of the emergency room, and offers psychosocial support to patients and their families.

White is especially excited about the prospects for enhancing palliative services in the new space that will soon be occupied by the organization in the Pepper Family Home Hospice and Center for Care. "The building will be open to the public, and we will be able to offer a spectrum of onsite services," she enthuses. "We will host **workshops and classes** on nutrition and treatment of symptoms. We will also have a **palliative care clinic** for people who don't qualify for home visits."

She adds that they will also be able to respond to the demand for more **complementary therapies**, providing onsite services such as aromatherapy, guided imagery, and yoga, in addition to those integrative therapies already offered such as massage, music, and art.

The new space will also provide additional opportunities to expand Hospice & Palliative Care of Northeastern Illinois **community and professional education** programs.

- Through workshops, meetings and classes, **educational programs** assist community members to deal with a given chronic disease or condition, such as diabetes. Other topics include preparing health care advanced directives and living wills: documents that facilitate care down the road, as well as, public education focus on dispelling myths about hospice and end-of-life care.

According to White, there's a lot of confusion and fear about end-of-life care. "If we can do our part to educate people and their families about the subject, let them know what their options are, and understand their choices, we are able to alleviate confusion, anxiety and stress around end-of-life issues.

- Hospice & Palliative Care of Northeastern Illinois also provides educational seminars to **professional health care workers**, including those who work with patients in nursing homes and other managed care environments on pain and symptom management as well as other specialized end-of-life issues.

White points out that many of these programs are covered by Medicare and private health insurance. She says that often people wait too long before taking advantage of the services that are offered, and urges people to act sooner to obtain full benefit from the programs.

"We hope that with the community resource provided by additional space in our new hospice home, we will have broader dialogue with people about hospice and palliative care and what their end of life options are," adds Musikatow. Throughout the year, Hospice Foundation of Northeastern Illinois raises money to provide the necessary financial support for several unfunded Hospice programs that are offered to patients and family members. She continues, "There's very little conversation about that, and we want the public to know what their choices are; we want you to know what we do!"

Just ask Sam's family.

### ***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](http://www.HospiceAnswers.org) and [www.PepperFamilyHospiceHome.org](http://www.PepperFamilyHospiceHome.org).

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