



Not so lonely a death

by VICKY CERINO

Frank talk about the inevitable eases fears for elderly and family.

Inside a white garbage bag sat Mary's possessions.

Clothes, stuffed animals and dolls were the only remnants left after 80 years.

The plastic bag, tossed on the floor of a nursing home office, was a forlorn reminder of a woman whose greatest fear was dying alone.

Although it was years ago, Sarah Thompson, Ph.D., can't shake that image. "(Mary) was very lonely and the nursing home didn't have anyone who could sit with her or just keep her company the last couple of days," she said.

Sadly, dying alone – or in pain – isn't uncommon, said Dr. Thompson,

who hopes to improve end-of-life care for nursing home residents.

“Nursing homes that deal well with death and end-of-life are a minority,” said Dr. Thompson, associate dean for academic programs in UNMC’s College of Nursing. “For all permanently placed residents, death is inevitable, but how residents die is not.”

Changes in palliative care programs – as well as more open communication about death – are urgently needed, said Dr. Thompson, noting that an estimated 40 percent of people over the age of 65 will die in nursing homes by 2020.

Fortunately, the dialogue for change already has begun. Last August, Dr. Thompson and her colleagues launched a \$1.6 million study funded by the National Institutes of Health to examine organizational structures and processes in nursing homes.

The study will focus on such areas as leadership, teamwork, communication and palliative care, assessing their impact on the quality of end-of-life care for dying residents and their family members.

“This study will give us a

tremendous amount of information and ideas for how to improve care,” said Dr. Thompson, who joined the college in November from the University of Kansas Medical Center School of Nursing. “It is one of the first studies of its size to gather this much information from family members in nursing homes.”

The four-year study will be conducted in 100 Nebraska and Western Iowa nursing homes with 60 or more beds. Researchers will collect information from about 2,500 family members and half of the staff in participating nursing homes.

The team includes co-investigator, Virginia Tilden, D.N.Sc., dean of the UNMC College of Nursing, who is nationally recognized for her expertise in end-of-life issues.

Families should communicate their wishes and not be afraid to discuss death, Dr. Thompson said. “The most important thing is to understand how a loved one views quality of life,” she said. “If you’re having conversations with someone, you begin to understand when enough is enough. The angst I’ve seen many families go through can be alleviated with ongoing discussions around options.

“Having these conversations are hard, but they’re really important because you begin to understand how to make decisions. If you can’t have those conversations because you are too afraid, get someone to help you – someone you know at the nursing home, your pastor or a friend.”

Understanding a loved one’s last wishes, or simply acknowledging a life lived, can lessen the pain and second-guessing that families and caregivers often experience, letting them better appreciate the final moments.

Mary – who gave up everything when diabetes and congestive heart failure forced her into a nursing home – understood how a simple act of humanity would have made all the difference to her.

“The way they treat death here makes you feel like a big nobody,” she once told Dr. Thompson.

Remembering Mary’s bag of life treasures, Dr. Thompson is more determined to improve end-of-life care for all nursing home patients. “By being alone, Mary’s biggest fear of being a nobody came true,” she said. 📖

Nebraska’s support for palliative care is growing. In April 2006, the Nebraska Hospice and Palliative Care Partnership brought together 11 Nebraska organizations with an interest in improving end-of-life care and conditions across the state. The partnership’s mission is to make palliative care available to those suffering chronic health problems, but who are not diagnosed as terminally ill.