

Lodi woman went through difficult times without Hospice

By Gail Riley

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My mother, a resident of Lodi for over 60 years, died in a Lodi nursing home last year at the wonderful old age of 92. But because our family was not advised of the availability of hospice services for nursing home residents, her last few months of life were not peaceful.

So to honor her memory, I would like to tell her community of this very special end-of-life option available to you or your loved ones.

First, let me provide an overview of hospice care in our country. In October of this year, President Bush signed a proclamation declaring November to be National Hospice Month. The proclamation reads in part: "Hospice enables many of our citizens to spend their final days in comfort and dignity surrounded by loved ones. This palliative care plays a vital role in our Nation's health care system, and the dedicated work of hospice care givers helps ensure that our citizens receive the services and support they need."

In 2005, 1.2 million people with life-limiting illnesses received care from one of more than 4,000 hospice agencies, representing approximately one-third of this nation's deaths. Cancer diagnoses accounted for 46 percent of hospice admissions, while the top non-cancer diagnoses included dementia/debility (17 percent), heart disease (12 percent), lung disease (7 percent) kidney disease (3 percent), with other diagnoses at just under 15 percent.

An article in the Journal of the American Medical Association published in 2000 addressed the issue of "Access to Palliative Care and Hospice in Nursing Homes." It cites that "dying residents experience high rates of untreated pain and other symptoms and that they and their family members do not receive adequate social and spiritual support. Hospice Care improves end-of-life care for dying nursing home residents by addressing these issues, but it is rarely used, even though most nursing home residents have incurable chronic diseases, and more than half have been diagnosed with progressive dementia."

Progressive dementia is what my mother had. She could no longer walk; she couldn't sit in a wheel chair unless a safety belt was used. She knew me most days but thought her beloved husband was still alive. He died in 1974 after retiring from the Lodi News-Sentinel. When she would ask where he was and why he did not visit her, I would say that he had been to see her that morning, and he was now home resting. She always accepted this with relief.

On my daily visits to help her eat lunch or dinner we had wonderful conversations about her childhood, my childhood and living in Lodi. But all of this was before her downward spiral, which began with a decrease in appetite and ever-decreasing weight.

In the month of October, four months before she died, I was invited to a care planning conference at the nursing home. It was there that I learned of the beginning weight loss. The staff in attendance said they would have the dietician review my mother's case and probably give her a soft diet and a power milkshake. They thought this would increase her food and nutritional intake. We also talked about her medications, which had all been prescribed that year: anti-psychotics for the behavior that comes with dementia, cardiac drugs for a new diagnosis of

congestive heart failure, sedatives for agitation and pain medication to be given "as needed."

In those last few months, my mother always seemed to be in pain. I could tell by her furrowed brow. When she could still communicate she would say she had a terrible headache. When the staff turned or repositioned her she would cry out in pain, her whole body stiffening.

A more consistent approach to pain management would have been a blessing, rather than the "as needed" one. Apparently this meant she would receive pain medication when I requested it or when one of the nurses thought to provide it; she could not ask for herself.

In November, she got pneumonia. After witnessing a week of growing discomfort, I asked for a chest X-ray. I thought that because she could not chew very well and had difficulty swallowing, she may have aspiration pneumonia. I was told that she did not have a temperature so she probably did not have pneumonia, but that they would get one to check for fluid build-up from the congestive heart failure. The X-ray confirmed pneumonia in her left lower lobe, the hallmark of aspiration pneumonia.

She was put on antibiotics, and I asked to have her diet changed to a pureed one. In response, the nurse said she would ask the speech therapist to do a swallow evaluation. A week later the therapist wanted to speak with me and said that my mother was not being cooperative. When I asked what the problem was, she said that my mother would strike out at her, shout profanities, and then clamp her mouth shut. She further told me that to fulfill California regulations she needed to be able to complete the evaluation before changing the diet. When I told her that my mother was in no condition to be cooperative and that a whole week had gone by with her not being able to adequately chew her food, we got into an argument.

Only after I burst into tears of frustration did the therapist tell me I could have the diet changed by speaking to the director of nurses. This story is just one of many that chronicled my mother's discomfort and pain in the last few months of her life, which could have been alleviated if only we had been offered the option of hospice care at the October care planning conference or any time afterward. And because I do not believe that my family's experience was uncommon, I am telling you my mother's story so that perhaps you will be better able to recognize when your loved one could benefit from hospice care.

I have since learned that my mother was a classic example of progressive dementia, with a predictable decline that begins with loss of appetite and weight. She was not in a poorly run nursing home. It is considered one of Lodi's finest, and I really do believe the staff was compassionate and did their best for her. But federal and state policies require nursing homes to provide restorative care.

To improve quality of care, regulations require the use of a comprehensive, uniform assessment system for all nursing home residents. These in-depth assessments are triggered by the presence of specific conditions thought to be indicators of inadequate treatment. Functional decline, weight loss and dehydration the very signs of terminal illness are used as indicators for potentially treatable illness and are red flags to state inspectors. Assessment protocols assume that care plans will include treatment to reverse these conditions, not protocols for palliative care. This disconnect with the reality of dying, however, disappears once hospice is allowed to enter the case.

Under Medicare regulations, the hospice agency assumes overall responsibility for management and implementation of a care plan related

to terminal illness. The nursing home is required to continue the same level of service and personal care as if the patient were not in hospice care, while the hospice staff provide added palliative care.

Services unique to hospice include expert pain and symptom assessment and management with an emphasis on quality of life, emotional and spiritual care and bereavement service for the family. I am sure that this nursing home and the many others in Lodi offer hospice care as an option, but it was not offered to my family. And in the year 2000, only one percent of our country's nursing home population was enrolled in hospice care.

This needs to change. Hospice is a Medicare benefit. It does not matter if you are paying privately for the nursing home or if Medi-Cal is paying for the care, hospice is an additional benefit. In fact, even if you do not have Medicare, hospice care is available to you regardless of your ability to pay as long as a Medicare-certified hospice agency is used. In addition, hospice provides all medications, services and equipment related to the terminal illness.

Hospice is not a place; it is rather a philosophy of care created to help people live with dignity, comfort and compassion at the end of life. My hope, in memory of my mother, is to help more people be aware of this very special end-of-life option for nursing home residents.

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