



## Hospice End-Of-Life Care-

## Nursing In The Presence Of Death

By Nancy K. Crevier

To be in the presence of Joan Thorburn is to be in the presence of confidence, compassion, and serenity. Yet her mood is far from somber, as her co-workers at Regional Hospice of Western CT in Danbury will attest.

Joan Thorburn is a hospice nurse, a specialty within nursing devoted to symptom management and/or end-of-life care. She has also, since 2004, been certified as a trainer for end-of-life care.

The concept of hospice, which originated in England and was pioneered in the United States in New Haven in 1974, provides expert home health care in a supportive, nurturing environment to patients with serious, chronic, or life-limiting illnesses, and to their families. It is a concept that has appealed to this nurse since shortly after her graduation from St Vincent's School of Nursing in New York City in 1967.

The focus for hospice nursing is different from that of traditional nursing says Ms Thorburn, who has always known that her goal was to work with dying people.

"We are accepting of the fact that we have moved away from restoration of the patient. We can offer comfort with good symptom management until death. The other big difference is that hospice is a unit of care for family and friends."

She goes on to say, "I'm not at all uncomfortable around death. I want to work day to day with dying people."

As a nursing student, she would often pull up a chair and just sit with dying people in the hospital. She realized early on that there was no need to talk, that merely her presence could bring comfort. What she learned was, "Never be



Joan Thorburn, a hospice nurse with Regional Hospice of Western Connecticut, Inc, will speak at the annual fundraising breakfast of the Newtown Chapter of Regional Hospice on June 14 at the Fireside Inn. Ms Thorburn has been a hospice nurse, providing holistic, in-home care for end-of-life patients, for ten years. -Bee Photo, Crevier

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afraid of silence. Never try to fill silence with noise." It is an important lesson that she has held dear her entire nursing career, and one which she freely shares with those new to nursing.

As a hospice nurse, Ms Thorburn has the benefit of working in her patients' homes.

"We look at the whole picture of what is happening," says Ms Thorburn, who has been a hospice nurse for the past ten years. In a patient's home, she can see the whole picture, including the patient's level of activity, how a patient lives in the home, and what the daily routine is like.

"The patient defines their care for the hospice nurse," says Ms Thorburn. "We give back to them the control of their life, give them a place to talk about what is happening."

What is often happening by the time a patient is referred to a hospice nurse, is imminent death. Referrals come very late, according to Ms Thorburn, and hospice nurses may be able to offer their services for less than two weeks. Usually a hospice nurse is called in to do palliative nursing, which focuses on symptoms, and ends up providing hospice, or end-of-life, care.

Hospice nursing requires a skilled ability to listen and hear a patient's needs, as well as a sensibility on how best to offer comfort and dignity to the dying.

"I look for cues from patients regarding death and dying," she says. "Patients are afraid that by acknowledging dying they will lose hope. I take you where I find you on this journey. I have no expectations - you don't have to take my advice. But we can always hope in comfort and peace until the end of our lives, maybe not in restoration."

There are other reasons for patients to accept hospice care. Palliative care medications are out-of-pocket expenses for Medicare patients, but with hospice benefits, medications, medical equipment, and other medical expenses are covered 100 percent. Hospice benefits also offer respite care, in which hospital or in-home coverage is paid in full when the caregiver cannot be present.

Hospice is a specialty that requires advanced training, Ms Thorburn stresses, and ongoing education in areas of pain management, new medications, updates on medication, and alternative therapies. The total, holistic approach absolutely has to be applied to hospice, she says. "The pain component can be psychological or spiritual."

The pain component also encompasses families and caregivers of terminal patients, says Ms Thorburn. Medical social workers, pastoral support, home health aides, and family support volunteers, in addition to the hospice nurse, make up the teams that help caregivers deal with day-to-day life. Nor does the work of a hospice nurse and the hospice team end with the death of the patient. Hospice workers continue to offer support and remain in touch with families up to 14 months after the death.

The most difficult thing for this hospice expert, "is to sometimes see the tremendous sadness and disharmony in families; and not every death is timely." While most of her hospice patients are older, she has provided comfort to young adults and children, as well.

"With children, the mother is the nurse," she states, "and I am helping the mother." In a sense, she becomes a helpful "visitor" in the eyes of the child.



Ms Thorburn believes it is her Christian faith that helps her maintain an upbeat attitude in a job that could easily wear away at the heart and soul of a less committed individual.

"I'm called to this work," she continues. "This lifts me up."

"I didn't know it [death] could be so peaceful," one family told Ms Thorburn.

"There's a lot of job satisfaction in hearing that," she says. "I made a difference."

Ms Thorburn will be the guest speaker at the 16th Annual Fundraising Breakfast for the Newtown Chapter of Regional Hospice on Tuesday, June 14, at the Fireside Inn. Reservations for the breakfast can be made by calling 270-1960 or 426-3651.

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