



Photo: Raja Hornstein

the intimacy of dying

Hospice care is “about having your heart broken,” but it is also “like slicing open a piece of fruit and seeing its sweetness,” says **FRANK OSTASESKI**, who has attended the deaths of more than 1,000 people over a 20-year period.

Frank is the founder of the Zen Hospice Project in San Francisco, running a five-person Guest House for the dying, and supplying volunteers to a 28-person hospice inside the Laguna Honda Hospital. He says that his work is “extraordinarily satisfying. I feel so lucky that I get to do this. If we welcome death as part of life, we can learn from people who are dying. It can be an extraordinarily intimate time. Sometimes I get very close, and when a person dies, I am very sad. But I wouldn’t have traded the experience for anything.”

The Guest House, located a half block from the San Francisco Zen Center, was once a bed-and-breakfast for Buddhist students of the center, converted in 1987 into a home-like hospice for the dying. There the dying pass their final days, each attended by a trained volunteer, a.k.a. “compassionate companion.”

Patients often arrive at the hospice full of anger and suspicion and two overriding fears, Frank says: that they will die in pain, and that they will die alone and abandoned.

At the hospice, he assures them, neither thing is allowed to happen.

“If a patient wants to be alone, he is left alone,” Frank says. “If he wants to talk, someone is with him. There is someone here to be a companion 24 hours a day, and if the person is in crisis, a volunteer is here around the clock.”

Frank has worked with ill or disabled people for much of his life. He grew up on a “great big rambling estate” on Long Island, “surrounded by woods, with greenhouses everywhere.” His father was a chauffeur. “It was a very beautiful, sensuous life,” he says – but there were problems, too: his father died when he was 16, his mother two years later, and “I was on my own very early.”

He studied psychology at college, and worked with inner city kids and as a caregiver for the disabled. Later, “I worked with several agencies like United Cerebral Palsy, and I got involved at the beginning of the AIDS epidemic.”

He suspects now that he was attracted to such work as

a way to avoid his own pain: “I thought if I was with someone whose pain was worse than mine, mine might not be so bad.” He says true compassion arises from exploration of one’s own suffering, “and you can use that experience to build a bridge to the person who is dying.” In his early 20s, he says, he wanted to be a rock and roll producer: “I was young, egotistical, driven by the idea of fame.” To satisfy that urge, and to raise money for agencies he worked for, he began staging rock concerts, “which turned out to be rewarding financially, but after awhile very empty. It wasn’t very satisfying.”

He took a year off to travel in Asia – Thailand, Burma, India and Nepal – “and travel brought me to Buddhist practice, to an appreciation of the impermanence of things and the reality of change.”

Back in this country, he traveled in Mexico, where he became involved with Central American refugees who had fled to camps in Chiapas. “We saw a lot of unrelieved suffering, and isolated, terrible dying, and I thought there ought to be another way to do this.”

In the early ’80s, he had begun caring for people with AIDS, and that led him to study with Elizabeth Kubler Ross, a pioneer who identified five different phases of the dying process, and “who saw dying as a kind of opportunity for people to wake up to their lives.”

Meanwhile, Frank’s Buddhist beliefs and his friendship with Buddhist teacher Jack Kornfield had led him to become the first director of the Spirit Rock Meditation Center, an hour north of San Francisco. He left in 1987 when he was asked to start the Zen Hospice.

The first patients at the Guest House were men Frank found on the street – homeless, untended, and dying, often of AIDS. More recently, the patients are more likely to be men and women with cancer who are OK financially, but are without family and fearful of dying alone.

From the beginning, his goal was to train people to give compassionate care to the dying. Of the 800 people who have been through training, many work at the Guest House or in the hospice at Laguna Honda hospital.

Trainees do not have to be Buddhists, he says, though many are. All must have an ongoing spiritual practice of some kind, to help them find common ground with their patients.

"Caregivers are most effective if they can say, 'You're alone, I'm alone. You're afraid, I'm afraid. The events of our suffering are not very different.'"

Lately, Frank has organized another training, which takes the work to the broader community, providing an expanded number of end-of-life counselors who can be called upon the way pregnant women call upon midwives – to provide guidance, advocacy and care to those facing death.

The first training will begin in January 2002. Participants, about 20, will be therapists, nurses, hospice workers and chaplains, people already experienced in work with the dying.

"This is a pilot project," Frank says. "The idea is to start a movement."

Frank prepares for his own death by exploring his personal pain and fears, and by making sure to tell family members and friends that he loves them. "I spend a lot of family time. I try not to miss my son's baseball games." He met his present wife, Vickie Restani, a nurse in the liver transplant unit at the University of California San Francisco, 12 years ago when she was a hospice volunteer. They have four children between them; his son Gabe has spent hours with him at the hospice.

He returns over and over to his "meditation cushion."

"It's very easy to be swept away in the drama. In my work, people want you to be someone special, and meditation reminds me of my ordinariness. You can't do this work and have airs about it – to act as if you are the good guy and the dying are the poor unfortunate ones. It's important not to think you are somehow better because they have lived on the streets and you pay ridiculous amounts of rent.

"People who are dying have great bullshit detectors. They know right away if you can be trusted." ❁

[From an article by Beth Ashley in the *Marin Independent Journal* July 8, 2001. Reprinted with permission.]



Ecie Hursthouse, right, with volunteer coordinator Joy Su

a voice to my suffering

Amitabha Hospice Service in Albany, north of Auckland in New Zealand, has just bought its first building for training and offices. Director ECIE HURSTHOUSE reports that the purchase of the property was largely made possible by ESTHER KOH, an "open-hearted, dedicated, multi-lingual dakini" from Singapore who provided a major part of the financial backing and who is the Service's live-in office manager. Established as a charitable trust in 1995, the Service offers free practical home help and compassionate companionship for the elderly and the incurably ill of any age and their families.

Volunteer caregiver, Monique Keenan, says, "What stands out most in working with Amitabha is what I've learnt and gained on the emotional level. For instance, my fear of offending when going into the homes of people from a different culture dissolved almost instantly. I found that an open mind and a warm heart with the right intent go a long way in overcoming one's personal obstacles!

"Very often just being there,

listening, sharing secret moments, laughter, are all very important ingredients when relating to patients and/or various members of the family who need a neutral person to confide in. For me it has been a wonderful growing experience, with much given and received."

Jean Hyland trained as a caregiver with the Service and her first assignment was with a Chinese woman, Bickleen Wang, who has motor neuron disease. As the paralysis took hold over her body, it became increasingly difficult for Bickleen to talk. An alphabet board was used to spell out what she wanted to say. Each letter was an effort, sometimes only a flick of an eyelid or a look in her eye was all there was to go by. Bickleen's determination to reach out over the chasm inspired Jean to try and capture their conversations and their mutual experience in poetry and prose. With the financial backing of Bickleen's husband, Jean's poems were published in a book called *Voice to My Suffering*. ❁

Copies of *Voice to My Suffering* are available for US \$10 from amitabha@stupaa.org.nz