

Sickness unto death, without despair

Hospice assists terminal patients to die in comfort and dignity

By NATSUKO UTSUMI
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One summer morning in 2001, a good friend of mine, Bronson Conrad, rang me at my Manhattan home. After we'd chatted for a while, he broke the news that he had incurable, terminal cancer in his hip bone.

"What do you mean by incurable terminal cancer?" I asked him, almost with annoyance.

"It means that I'm dying," he said.

No! How could anybody seem so unperturbed at making such an announcement?

I cannot remember what I said afterward, but I was crying and trying to make him tell me that there was even a faint hope of recovery. It was supremely ironic that he was the one doing the consoling as I became distraught.

Bronson invited me to visit him in Toronto while he was still strong. He was only fifty-something then, a tall and sturdily built former Canadian Army officer who had made his fortune starting up an Internet company and other businesses -- even a diamond-mining concession.

Always an energetic risk-taker, he had enjoyed an adventurous life and, as an avid recreational pilot, had flown around the world twice in his own plane. On the second of those flights, in 1999, his wife and two sons accompanied him on what, unbeknown to any of them, would turn out to be their last family trip.

A week or so after his call, I flew up to Toronto. Frankly, I had had no idea what to expect. As soon as I walked into his home, though, I relaxed as I saw my dear friend sitting up and smiling on a high hospital bed in a living room whose panoramic windows look out over a terrace to a small wood.

During my visit, Bronson made and received several business phone calls, and because he was calm and alert, we talked about the fun times we'd shared.



NATSUKO UTSUMI PHOTOS

Above: Michael Alfonso, then 7, and his younger brother Sebastian, 4. Michael, who was born with cerebral paralysis, was placed in a home-hospice program after suffering an attack of acute respiratory failure. Bottom: Connecticut Hospice physician Diane Smith ministers to Michael in his room at home while hospice nurse Arlene Wisneski sits by the window. Michael died two weeks after this photograph was taken.



Momentarily, it was easy to forget that he was dying.

It was not so easy, however, when he talked about his horrendous pain. That was controlled, he said, by morphine-based medication that he administered himself when he needed it by pressing a button on a portable pump called a "syringe driver," which subcutaneously injected just the right amount to alleviate his pain without making him lethargic. Despite the fact he was getting weaker from the cancer, he could still talk and even laugh almost like he used to. Nevertheless, my emotional but rather inconsiderately strong goodbye hug made him wince.

Bronson died three weeks later.

Though that was the last time we met, it was the first time for me to encounter the "home-care hospice" system.



Top: A life-size bronze sculpture in the Connecticut Hospice compound portrays the partnership forged between the patient, family and nurse. The torch held by the nurse never goes out. Bottom: Family members watch as hospice nurse Lauren Tolla prepares Walter Lechowicz, who suffers from a nerve-degenerating disease, for his bed bath.



Basically, hospice and palliative (or symptom-easing) care, whether in-patient or at home, aims to enable terminally ill people to live out their remaining time with dignity, and as long as possible without pain or suffering. Pain and symptom control is at the heart of this specialist medical field. In practice, it means that patients, and their families, receive interdisciplinary medical support, as well as spiritual support.

In June, I visited Connecticut Hospice in Branford, near New Haven. It was America's first such program when it was founded in 1974, when Brooklyn-born nurse Rosemary Johnson-Hurzeler began an in-home hospice service funded, for the first three years, by the National Cancer Institute. (Today, there are some 2,400 similar programs throughout the United States)

In 1980, after Connecticut Hospice acquired a building, it was able to offer palliative care to its first in-patients. As a basic rule, only patients diagnosed as having no more than six months to live are admitted, and not for curative treatment or extensive life-support.

Standing inside the new, semicircular three-story building, it felt almost like a small resort hotel, overlooking, as it does, a beach on the New England coast. The all-glass lobby is a bright, wide-open space from which I could look over a green lawn and see boats going by. The second floor is for patients and has fireplaces and tasteful paintings in the hallway. The ceiling is decorated subtly with stars and moons, so that they have something pleasant to rest their eyes on when they are transported from their rooms.

In other words, the goal has been to make the remainder of their lives as comfortable as possible -- they can share almost unrestricted time with their families and friends, take care of unfinished business or just relax in peace.

As Johnson-Hurzeler, a platinum-blond woman with a gentle voice yet

commanding presence, explained: "Death is but an instant in the comparatively long continuum of one's life -- life that should be celebrated and savored up until its very last moments." With the support of friendly doctors and nurses -- and nowadays mostly paid for by Medicare and private insurance and philanthropic donations -- Connecticut Hospice's care is all about what's known as Physician Assisted Living (PAL), not about dying.

PAL focuses on the dialogue between physician and patient. Clearly, the physician's role is pivotal in preparing patients for the possibility of advanced and irreversible illness. But, of course, final decisions on whether to be in the in-patient hospice or hospice home-care -- or even whether to go back to a regular hospital -- are for the patients to make.

In April last year, cervical cancer patient Michelle Quesinberry, 48, was told that she was terminally ill. Looking back, she said, "I have never been a quitter, but there was nothing I could do."

As cancer was gnawing her life away, I visited her at home and found her "living one day at a time" with the aid of painkillers and a morphine pump. She said that talking to visiting home-hospice doctors, nurses and social workers gave her an enormous amount of support, especially because they tell her what's happening and don't just dole out medication.

"I wish to be happy till I go," she said. "I just want to spend some time with my family." Hospice care enables Michelle to stay at home to be with her 83-year-old mother. "My mother keeps me strong," Michelle said lovingly.

Hospice care is not designed solely for patients, but also to support anxious family members going through such a trying period, and the inevitable bereavement.

Another home-care patient I met was 61-year-old Walter Lechowicz, a victim of Amyotrophic Lateral Sclerosis (ALS), a progressive nerve-degenerating disease that eventually leads to muscle weakness, atrophy and death. He was immobilized from the neck down and unable to speak. Since he learned that he had this incurable disease 18 months earlier, his family had been taking care of him at home -- as was his wish.

"We see him get worse and worse every day, but I tell myself that we still have time," said his wife Diane. "He cries, but all we can do is just give him a hug and let it pass."

Home-care nurse Laruen Tolla comes twice a week to take care of him, but also dedicates a lot of her time to supporting the family, which, like all families in this situation, is under tremendous emotional and often practical stress. As Rosemary Franco, another nurse, put it, "Our patients and families are angels, but sometimes they are flying low to the ground. It is the privilege of nursing to be



Above: Lung-cancer patient Jane Albert pets certified therapeutic dog Ipsy Pipsy. Bottom: Cancer patient Michelle Quesinberry, 48, and her mother relax during a home visit by hospice nurse Marcy Holland.



their other wing. We learn from patients and families always."

Despite the burden on them, however, most families apparently want to be involved in patient care. "Our help includes outreach for the family," said clinical supervisor Sylvia van Heerden. "Caring for the [dying] family member also helps to reduce their fear, because they are actually doing something; they are involved in taking care of the patient. Toward the end of life, people lose a lot of control, and in a way it gives some control to the family and to the patient, as they are actually involved in their own care by making decisions."

For family members, the experience of sharing the last days of a loved one's life is very precious.

Among the many I spoke to was Peter Yarrow (from the folk band Peter, Paul and Mary, and today an advocate of the hospice movement). Speaking of his work, he said "This is the most spiritual time in my entire life."

Years back, he spent the last three weeks of his mother's life at her bedside in Connecticut Hospice, sleeping there and singing for her. Thinking back, he said the experience changed him for the rest of his life, as he feels he has "never loved anybody with such freedom and honesty."

"With dying loved ones in a hospice, there is no point in lying or talking trivia," he said. There, love transcends everything else.

To learn that we are dying is the most horrifying moment in life. How can anybody live with such unfathomable apprehension? And is it right to inform people their days are numbered?

From her 22 years of experience, van Heerden said, "A lot of the fear of dying is because people are not informed. Often you can talk to them, about what it is, and what's happening to them, and a lot of the time fear will subside, because they are informed. Then they can start thinking of important things, instead of fearing, and refocus on other aspects of life."



Jane Albert during a consultation with Connecticut Hospice chief physician Dr. Todd Corte.

On my last day at Connecticut Hospice, I was sitting with Dr. Todd Corte and 53-year-old lung-cancer patient Jane Albert, who started to weep while telling the doctor about her condition. She was a teacher for the blind, and had married only three years before. Although cognitively she must have known that she would die, I could see that she was clinging on to life, even wearing perfume and a wig. Her pain and symptoms were under control, but her sadness was not.

Corte said to her with utter sincerity, "I wish I had pills for you to ease sadness."

From an outsider's perspective, it seems that for doctors and nurses working in a hospice, the hardest thing must be that they hardly ever see patients recover or be discharged, except in rare cases of cancer remission. Every day, four or five patients pass away. Still, because the goal of doctors and nurses at Connecticut Hospice is to ease suffering rather than cure illness or prolong life, my impression

was that they did not necessarily see death as failure.

Of course, that doesn't mean the job is easy. Staff hold what they call a "daily huddle," in which they sit together and share their experiences, thoughts and feelings. The result is that they all work together as a therapeutic support group.

Altogether, my abiding impression is of tremendous bravery from everyone I met at the hospice, whether they were staff, patients or families. Most of the patients had undergone every treatment modern medicine can offer, only to learn after so much suffering and so many dashed hopes that there was nothing left to do but entrust the rest of their lives to fate.

Yet what I saw was people not just letting go and living in despair or anger, but choosing to live positively until the end, and to enjoy as much quality time as they can. Such humility, combined with an appreciation of life, bestowed upon most patients a serenity that was profoundly moving to witness.

If the day comes when a doctor tells me that I am terminally ill, I don't think I will be so courageous, and I am sure I will go through a serious grieving period. But then, I hope, I will be able to find support at an compassionate and competent place like Connecticut Hospice. I would also be sure to call everybody I have ever loved to say that I love them, and apologize to everybody I owe an apology to.

Dying with peace of mind, free from unnecessary life support: This is the ideal I learned from my friend Bronson and from Connecticut Hospice.

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