

San Jose Mercury News

HOSPICE MEETS EVERY NEED – ONCE YOU'VE DECIDED TO DIE

SAFETY NET EASES THE WAY FOR DYING FATHER, HIS FAMILY

By Tia O'Brien

I was a novice at coping with death. Then, in March, I endured a rugged immersion experience. My father was hospitalized, diagnosed with incurable leukemia, and died -- all within four weeks. It was a brutal episode that played out -- and continues to play out -- in an intensely sad family drama. Imagine a blend of Faulkner and Fellini: a dark plot punctuated with ironic, bizarre moments; a saga complete with estranged relatives, haunting family secrets and deathbed reconciliations.

I dealt with two unsettling realizations. The first is that our health care system provides more complete, low-cost medical and emotional care for the terminally ill who opt to die at home than for the sick who struggle to live. The second is that death is never just about the end of one person's life. When my father died two days shy of 86, our family -- as we knew it -- also died.

We needed not just doctors and nurses to help us deal with his sickness, but social workers and counselors to cope with the practical and emotional consequences of his death. Thanks to the last major decision my father made -- to die at home -- we got that help, and Medicare picked up the tab.

My father, a crusty former journalist living in the suburbs of Washington, D.C., was a brutal realist who dreaded a protracted, tortured end. In the past two years, as his health declined, he'd wave his cane at a photo of his good friend Jack and proclaim that Jack had done it right -- he died instantly from a heart attack. Within an hour of receiving his fatal prognosis, my dad informed my mother that he wanted to die at home, and as quickly as possible.

Overnight, he started receiving the benefits. By waiving his right to future

curative treatments and having less than six months to live, my father qualified for what I now refer to as medicine's Gold Plan: hospice care. The day before receiving his diagnosis, he was worrying about mounting medical bills. The next day, those worries were gone. Once someone over 65 is designated a hospice patient, federal health insurance pays for nearly everything, thanks to the Medicare Hospice Benefit.

That benefit, approved by Congress in 1982, came as Congress struggled to lower the nation's skyrocketing health care bills. Lawmakers thought the hospice approach delivered compassionate care for the dying. But they also liked the bottom line: They decided it would be much cheaper to die at home than in intensive care.

Because choosing hospice means accepting death, doctors -- focused on prolonging life -- often don't suggest the option until the very end. In our technologically advanced society, with myriad new treatments available, it can be difficult for doctors and patients to stop trying for a cure. But the reality is that given the way our health care system works, the only way most people can get the kind of comprehensive care hospice offers is by making the choice to die.

Hospice is not a "place" but a nationwide network of more than 3,100 community-based groups, mostly non-profits, dedicated to helping the terminally ill of all ages end their lives on their terms, as comfortably as possible, surrounded by family and friends. It's a unique health care model because of its team approach, which addresses every aspect of life and death, from managing pain to spiritual growth. Hospice puts a premium on supporting families as they

struggle through the patient's last days and the following weeks and months that can tear survivors apart -- or apart from each other.

My family needed all the help it could get. We were a tiny crew. My mother, who uses a wheelchair, deftly worked the phones calling physicians, and my parents' saintly caregiver did the bulk of the nursing. My brother couldn't help -- he was in a nearby nursing home, suffering from advanced Parkinson's disease. That left my husband and me trying to help nurse my father, finish his taxes, meet the attorneys and make funeral arrangements while coping with relatives in varying states of distress.

My mother, a veteran warrior with hospitals and doctors, was highly skeptical when the hospice nurse first arrived at the apartment and pledged that we no longer had to battle for good care. The nurse, our hospice team leader, vowed that team members would function as our advocates -- meeting regularly to assess the family's needs, calling doctors and arranging prompt drugstore deliveries. Although we had to provide most of the hands-on nursing care, our home-health aide, nurse and social worker would make regular visits.

If we needed help, the nurse instructed us to phone the hospice, any time, 24 hours a day. Within 15 minutes, she said, we would get a return call and, if there was an emergency, a nurse would try to be at our house within half an hour. This, said the nurse, was a health care system that works.

Why don't the seriously ill get such Cadillac-style support? Experts say that in a medical system driven by advanced diagnostic techniques and

treatments, most insurance plans don't even have a mechanism for team payment. "If there isn't a specific reimbursement code for team care, then there is not an incentive to provide it, because the doctor may be reimbursed but not the social worker," says Dr. Alan Garber, director of the Center for Health Policy at Stanford University.

Even before my father arrived home from the hospital, the contrast between his care as a seriously ill patient and a terminal patient under hospice care was stark. His doctor authorized five more days in the hospital, courtesy of Medicare, to stabilize him. Only 10 days earlier, he'd been plucked from his hospital bed and dispatched to the nursing unit of his retirement complex, even though his doctors couldn't nail down a diagnosis and had no treatment plan. Insurance simply wouldn't cover continued hospitalization.

Despite severe nausea and weakness, he was supposed to trek back and forth to the hospital a couple of times a week for transfusions and more tests. This questionable plan fell apart when his blood count dropped off the charts. He was rushed back to the hospital in an ambulance. That's when his condition was declared untreatable.

Once the hospice team kicked into action, the system did, indeed, work. Our calls were returned within 15 minutes. And help did arrive quickly. On Easter Sunday, we placed an emergency request for a social worker. Two hours later, she was sitting by my father's bedside. My father had not always approached life in the most peaceful fashion and now was weighed down with unfinished business and feuds. For 86 years, he'd refused to discuss the physical and emotional abuse he endured as a child and the subsequent anger that filled his adult life. Now he urgently needed to talk. She listened.

Two days earlier, he'd asked our social worker to help him reconcile with his younger brother, whom he hadn't spoken to since 1982. The social worker left a message on my uncle's answering machine explaining the situation, then held the phone up to my father so he could add his own message. That afternoon, my uncle finally broke his silence and called back. As the elderly brothers filled in 20 lost years, they wept.

The rift that had torn my uncle and father apart is exactly the kind of family fracturing that hospice works to avoid by including social workers on each team. The feud had started with a fight over the date of their mother's funeral. In the volatile atmosphere of death, long-simmering tensions easily boil and can rupture families apart.

Our family's death play was so complex that we were primed for a falling out, especially as we grew increasingly exhausted. Some alienated relatives never called. And my mother wrestled with whether to risk upsetting my terminally ill brother with the bad news. The social worker assured her that he should be told. One hour later, my brother was sitting in his wheelchair by our father's bed, saying a very private goodbye.

We were even forced to play a sort of Birthday Russian Roulette in those final days. My dad arrived home as our family entered our zodiac zone: five family birthdays -- including my own, my daughter's, my husband's and my dad's -- scattered through an eight-day stretch. Would one of our birthdays become a reminder of my father's death? Or would he, in a twist of fate, die on the day he was born 86 years earlier?

Without the social workers' support, we all would have crumbled. Instead, we often doubled over with laughter, like the time my mother discussed funeral arrangements with our social worker. Although my very capable Turkish mother speaks fluent English, some words still get tangled up.

"My husband wants to be fumigated," she explained matter-of-factly.

"Fumigated?" the shocked woman replied, trying to muster her most soothing tones. "Do you mean cremated?"

My mother nodded pleasantly, "Yes, that's it. Cremated."

And then there was the time she shocked the doctor with a request for a "do not resuffocate" order, better known as a "do not resuscitate" order.

On my father's seventh day at home, April 2 -- a non-birthday -- he died. To prevent panic, the team researched my father's illness and schooled us in what his death might look like. "It isn't pretty, like in the movies," the nurse stressed.

Thankfully, my dad's death was as peaceful as in the movies. He was at peace, but I was not. At 6 p.m., three

hours before his life ended, the phone rang. I answered.

The caller -- someone who hadn't reconciled with my father -- suddenly burst out with an ugly truth: a dark, long-held family secret. Reeling, I hung up.

I had arrived at my father's deathbed eager for closure. Instead, I now had to confront seriously revised family history. I was tempted to walk away. I might have, if there hadn't been a social worker and grief counselor ready to swoop in. Even as we were making funeral arrangements, they started talking me through my tangle of raw, conflicted feelings.

The hospice team also counseled me on preparing my mother for a quick move into a new home, where professionals could take over the caregiving my father had provided. Having to leave her apartment was a miserable reality for a woman who had just lost her companion of 63 years. The team provided names of geriatric social workers who have been visiting my mom since I flew back to California.

After I returned home, I learned that a friend's mother had died one day after my father. Her mom's doctor had thought it was too soon for hospice care. When the death sparked a painful family rift, no one was there for damage control. After I described my experience, my friend discovered our local hospice would provide grief counseling -- on a sliding scale -- even though her mom hadn't been a hospice patient.

When my father opted for hospice, he gave our entire family a gift. In tallying up the costs associated with death, few people factor in the hidden expenses of broken families who never get treatment -- or of broken people. Hospice officials cite studies indicating that during the first stress-filled year after a death, health problems for those who are grieving escalate.

I've already scheduled my first of several Medicare-funded sessions with a bereavement counselor. I need to grieve not just for my father, but for the family I loved as child and have lost.

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