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Dying at Home

For 30 years, the hospice movement has helped terminally ill people find their way to a "good death".

BY STEVE HEILIG

Yesterday, over 65,000 Americans died. It was a pretty normal day in that regard.

Although there are no guarantees, most people who die in the United States are relatively elderly and die of heart disease, cancer or other chronic diseases—and the process of becoming ill and dying takes some time. Unlike only a century or so ago, most die in some sort of "institutional" setting—a hospital, nursing home and so on. A relatively lucky few die at home. And the luckiest few of all are receiving hospice care for some time before they die—wherever they die. At the other, negative end of the spectrum, a dying patient can end up the subject of much argument and controversy, as the national media and political debacle over Terri Schiavo's final days in Florida tragically illustrated last year.



A full generation and more has passed since the first modern hospices were founded in England in the 1960s and then in the U.S. in the 1970s; but this most humane and praised and logical approach to dying remains something of a mystery for many people. If something is called a movement, it usually indicates an uphill battle for acceptance, and that is true for hospice care. In fact, the first classic book on the topic was titled *The Hospice Movement* and was written by Sandol Stoddard in Tiburon in the 1970s. For many years both her book and Dr. Elizabeth Kubler-Ross's equally classic *On Death and Dying* might have been the only books on death and dying on the shelf at the average bookstore. Now there are whole sections on the many issues related to death and dying.

Yet hospice—the actual, practical, skilled-team approach to the physical, mental, emotional and spiritual needs of the dying—is still used by a minority of people in their final months, weeks and days. Of all dying people in this country, only about one-fifth utilize hospice care. To be fair, many of those who did not were not appropriate candidates for various reasons. But even among those who would benefit, only 40 percent receive hospice care. And therein lies a number of tricky issues, which a number of Marin people are working hard to address—with international implications. In fact, Marin has long been a locus of some of the pioneering efforts to improve how people die, a goal that could affect every one of us—whether we want to talk about it or not.



The formal organization known as Hospice of Marin was the second program of its kind founded in the United States, incorporated here in 1975—just a few years after the first such efforts came to this country from England. Last year, HOM moved into new headquarters in Larkspur and also endured a round of staff layoffs that were undertaken, amid some controversy, to preserve revenue and services.

Hospice of Marin president and CEO Mary Taverna, a nurse, is also currently chair of the board of National Hospice & Palliative Care Organization. She was involved very early on with the fledgling local organization, and after a hiatus, is back in charge.

Taverna describes hospice services as "a specially designed program which addresses the comprehensive needs of a family system at the end of life." The primary focus is obviously on the ill person and his or her medical and comfort needs, but equal attention is given to family members. With guidance and support, they learn how to

care for their loved one, they receive help making decisions and they have their own needs—around impending loss and death—addressed as well. Hospice defines “family” as anyone so designated by the ill person—so it’s not only biological relatives. The hospice team includes doctors, nurses, social workers or counselors, chaplains, physical or other therapists as needed, and volunteers, who are critical as they provide the practical support for daily needs.

And what does that mean for the dying person? Rachel Naomi Remen, physician and best-selling author of the well-received books *Kitchen Table Wisdom* and *My Grandfather’s Blessings*, has been involved with hospice issues for decades, and has seen the impact. “I fear many of us tend to take the existence of hospice for granted,” Remen cautions. “I’ve had family members die in places that do not have any hospice services and you would just not believe the positive difference hospice can make.”

Remen, who lives in Mill Valley and works at Commonweal in Bolinas, also has high praise for Hospice of Marin: “Marin has one of the premier hospices in the world and much of that is due to Mary Taverna. Nobody else has managed to take a hospice through all the changes in funding, medicine and so on with this very high level of service for 30 years. There was a time when hospices were folding up right and left because of reimbursement issues. People just gave up, but Mary never did. I think Mary’s not only a Marin treasure but a national one, as Hospice of Marin has served as a model for hospices around the world.”

Hospice of Marin serves about 235 patients per day in Marin, San Francisco and parts of Sonoma County, mostly in their own homes and in residential facilities. Medicare, the federal program for those over 65 years of age, is the most prominent source of insurance coverage of hospice costs, which average around \$190-\$240 per day, depending on the kind of medications being used and other factors. The average hospice patient is referred from a hospital or physician, who must certify—try to predict, really—that the patient has less than six months to live. Patients here receive hospice services an average of 62 days until death. This “length of stay” is growing, which Taverna sees as a positive trend.

“Ideally, the longer someone gets hospice care the richer the experience, as we are able to work with them to address issues that possibly haven’t been dealt with in a long time, if ever—relationships, and so on.” she notes. “Twenty years ago it was more like a 90-day average and then it shrunk back to a much shorter stay, and now the trend is back towards a more reasonable length. That’s for a couple of reasons—first and foremost, the referral sources are far more comfortable referring at an earlier time, and also many people are living well and longer with medical interventions, such as chemotherapy, which can be more gentle than it was before, so patients come to us in better shape.”

One relatively new program that helps extend the length of time that patients receive such optimal care is a partnership with Marin General Hospital, Taverna reports. “This is an exciting collaboration where Hospice of Marin provides a nurse skilled in palliative care and a social worker to patients with a longer than six-month prognosis. We thus get an earlier start on tough questions, such as the level and type of care that is best at each stage of the patient’s care. It’s been very well received by both patients and staff.”

Some of the more contentious issues hospice professionals have had to deal with include treating pain. Many more effective pain medications have been developed in the past decade or so, but regulations aimed at curtailing drug abuse and the issue of “assisted suicide” have hampered optimal use, as many physicians and other clinicians are spooked by the specter of investigation and discipline. However, the evidence is that the problem of under-treatment of pain impacts more people than real or supposed overuse. A recent California law, in fact, mandated that almost every physician in the state has to take a full day of continuing education in pain and other end-of-life issues.

Taverna agrees that pain treatment has improved. “The most predominant clinical need is for symptom management, such as pain or other discomfort such as breathing difficulty, and the interventions hospice now uses are incredibly effective,” she says.



In addition to the improvements in actual services offered to dying people, Marin

residents have been at the forefront of the broader and deeper issues surrounding death itself. Martha de Barros of Muir Beach was a volunteer at Hospice of Marin in the early days, and then went on to co-found hospice organizations in San Francisco, including the renowned Zen Hospice Project. She reflects that the "movement" has had profound effects on how many people deal with mortality.

"I started volunteering at Hospice of Marin in late 1970s, as several of my family members died in rapid succession, without hospice care, and I was both emotionally distraught and also curious about how we treat the dying in this country" she recalls. "I had heard about hospice but it was something that people didn't even know how to spell then. It was all new to me too, and I found some answers by joining with Hospice of Marin. So it was quite personal. I was looking for a better way—and I found it there.

"The overarching improvement is that death has been taken out of the closet, so to speak, as it was hidden away and seen as a failure of the attempt to 'cure,' " says de Barros. "But finally there was the realization that if people could find a good way to die at home, this was the best offering we could give them, to be with their family and pets and so on. So at the start it was all about bringing the person back home, and putting together a care team to meet all their needs. We try to find out what was most important to people in their lives and make sure that we maintain as much of that as possible as they are dying. For me, my Buddhist practice has always been centered here at Green Gulch Farm and our founder there, Suzuki Roshi, always told us the dying are our best teachers."

Also steeped in that tradition is Frank Ostaseski, a Mill Valley resident and another co-founder of the Zen Hospice Project. After leading that organization for 17 years, he left in 2004 to start the Alaya Institute, devoted to filling the real need for more awareness about issues of dying and death.

"When we started the Zen Hospice, it was the height and center of the AIDS epidemic, I had friends who were dying, and it seemed there were better ways of caring for them as they died," he reflects. "I was especially interested in the spiritual dimensions of that, and wondered what difference it might make to put people into the room who were calm, not afraid, and trained to deal with whatever came along, to do the ordinary things that are needed with awareness of how those can impact a person's final times."

Ostaseski echoes Taverna's feeling that death is just not something humans confront very easily in modern times—if they ever have. "I think there is something in the American psyche that leads to resistance to hospice as it can be seen as a kind of 'giving up.' And on a deeper level, I'm still not sure that the human egoic structure really can face our dying process. So people need support.

"The hospice approach acknowledges the naturalness of the dying process, and recognizes that there are certain opportunities at the end of life that are perhaps unlike any others, for human growth" he continues. "People then can open up in ways that up until then they could not do. Hospice brings a bigger model than just the medical model. The medical model still dominates, but the big improvement is that hospice is widely available across the country and has been accepted into the mainstream of medicine, with huge advances in symptom control and pain management. However, as it has adapted itself to the medical model, hospice has sometimes forgotten its spiritual roots."

Ostaseski's new work is aimed at deepening hospice work, in keeping with his long experience, and he has gathered a veritable all-star team of faculty to help teach about that, including Remen, Ram Dass, Angeles Arrien, Norman Fischer, Charles Garfield—founder of the famed Shanti Project—and others. Students come from around the nation for a yearlong intensive program on all aspects related to mortality.

"One of the things we're trying to do with the Alaya Institute is to remind the public and hospice organizations that this is predominantly spiritual work, not medical—what medicine can do is extraordinary, but it's not enough. So we've put together a renowned faculty to teach values and approaches to doctors, mental health nurses and healthcare educators, all of whom regularly deal with death. So we are trying to foster mindful and compassionate care of the dying in places traditional hospice programs don't always reach, and to train people from around the country to become inspirational leaders back in their communities and institutions...Beyond training healthcare providers we offer public workshops that emphasize the

relevance the lessons learned near death have for living a more loving and compassionate life. The best preparation for death is surely a life fully lived.”

Remen agrees with that perspective, and feels that “Frank has assembled a group of people to focus on the more spiritual side of end-of-life issues, to take care of the spirit not as an adjunct but as a central goal of hospice care. And I think he was probably the first person in the country to take that on full-time and in such an open way, and to train others to do so. So we are now training people who might be seen as midwives at the end of life. I’ve always thought of both birth and death as processes that often involve enormous physical challenges. At the end of birth, of course, you get to hold the baby and the pain of labor recedes with time. But when someone dies we don’t get to hold the soul, or whatever is departing the body, and sometimes the pain and stress of that loss can affect a family for many years, and cause people to have very deep regrets that they have to live with the rest of their lives. We try to get people to see the time of dying as what it really can be, a time of deep meaning, and even fulfillment.”



One clear trend is that there will be an ever-growing demand for such services and approaches, nationwide and perhaps especially in Marin. The much-remarked “graying” of America, with ever more people entering their “golden years,” is really only getting started. The demographic bulge of the baby boomers, like it or not, will involve more need for hospice care. Hospice of Marin’s Taverna reports that her organization is well aware of the trends and plans to be ready. And as Frank Ostaseski observes, “Here in Marin there is a large cohort of people who have always been interested in growth of all kinds, and in having choices and control over their lives. They’re going to want to have that at the end of their lives as well.”

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