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A KINDER DEATH



MARIA J. AVILA — MERCURY NEWS PHOTOGRAPHS

Diagnosed with terminal cancer, Greg Bartschenfeld, left, chose home hospice care so he can spend his remaining days with his wife, Dana Hopkins, instead of in a hospital.

Valley health care providers work to comply with patients' wishes to die in peace and comfort, rather than fighting the inevitable



Pain management helps control end-of-life costs. Advocates say the best care isn't necessarily the most expensive.

By April Dembosky

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The vast majority of Americans say they want to die at home with their family. The vast majority, instead, die in medical institutions surrounded by machines and strangers.

But in the South Bay, several health care providers are working to comply with patients' wishes to die a better death. From launching pain management programs to insisting on new vocabulary for end-of-life care, they want to redraw the line between fighting death and accepting it.

"The American perception is that death is optional," said Dr. Shoshana Helman at the Santa Clara Valley Medical Center. "We've lost sight of the fact that we're mortal human beings."

The local efforts, part of a national movement, could

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save the country's overburdened Medicare system thousands of dollars per patient — a significant sum for San Jose hospitals, which, a recent study found, opt for aggressive, costly, and usually futile, treatments more often than many of their peer institutions elsewhere.

"The best care at the end of life is not always the most expensive care," said David Kessler, co-author with Elisabeth Kubler-Ross of "On Grief and Grieving." "A respirator, dialysis, chemo on the day of death does not usually make for a good death. It's a hard message to understand in a society where the more you spend, the better stuff you get. But not in this case."

Comfort, not cure

National consensus has been reached in recent years on the benefits of two alternatives to the never-give-up approach: palliative care and hospice. Palliative care centers on managing pain at any stage of disease; hospice care, traditionally delivered at home, focuses on comfort in the last six months of life, rather than cure.

But advocates still face numerous barriers to altering the "do everything" medical ethos. Doctors fear being sued if they don't try every medical intervention. Care is fragmented among dozens of specialists, so decisions are based on individual diseases rather than the whole person. And medical professionals are trained to act, not initiate difficult conversations better suited to a psychotherapist.

"It's easier to go 'OK, I'm going to do everything,' than to really take the time to get a room full of adult children and say: 'Your mom's body is shutting down and this is the end of her life,'" Kessler said. The lack of communication often leads to a snowballing series of tests and treatments. "The ICU becomes a fast-moving train that no one wants to jump off of and no one prepares them to."

Palliative care is one strategy proven to slow the chain reaction and manage costs. Good Samaritan Hospital began implementing a formal palliative care program in



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When his medical team told Greg Bartschenfeld there was little they could do stop his cancer from killing him, he and wife Dana Hopkins decided they would spend their final days together at home, with Bartschenfeld in hospice care.



Nurse and case manager Pamela Deamant of Hospice of the Valley performs her weekly check on Bartschenfeld.

January. O'Connor Hospital, El Camino Hospital and Valley Medical just established such programs in the past few years. Regional Medical Center of San Jose wants to strengthen its ties to local hospice providers, while the nonprofit Hospice of the Valley is conducting a strategic plan to figure out its

role in breaking down stigma around hospice, and improving access to its services: in-home palliative care, help from social workers, and spiritual and bereavement counseling.

"The No. 1 thing we hear from patients is that they wish they had found out about hospice sooner," said

Sally Adelus, CEO of Hospice of the Valley. Medicare pays for hospice up to six months before death. But only 6.4 percent of Hospice of the Valley's patients come to them that early. Almost half come just two weeks before they die.

The mere presence of a palliative care program in a hospital moves end-of-

life conversations up on the agenda.

"My job is to recognize when death is on the horizon," said Helman. "And help people prepare for that in a way that allows them to be less afraid, by talking about these things instead of pretending they're not there."

Helman describes dying as a healing process. Not the healing of disease, but of relationships. When patients focus on being comfortable, they have more time to reconcile with family and explore their spiritual beliefs. Or they can finish one more project in their wood shop, drive a Ferrari, or take a trip to Hawaii, China, Reno.

Husband, not patient

Greg Bartschenfeld decided to marry his soul mate. He was falling deeply in love when he found out last fall that his throat cancer had returned and spread to his lungs, arms and legs — beyond what medicine could fix. Now 58, he went through aggressive chemotherapy to "buy some time," but stopped in January and began hospice so he could spend the last months of life being a husband instead of a patient. He

and his sweetie, Dana Hopkins, married in February.

"We were practically living at Stanford," he says of the 11-hour days of chemo. The stream of doctors prodding him, and the sense of powerlessness were exhausting. "I don't want to spend another day in the hospital."

"Being in the hospital makes you depressed," said Hopkins, 57, herself a cancer survivor. "It kills your spirit. Greg's spirit was what kept him going."

For the last six months Bartschenfeld has been at home producing videos, going on romantic weekends to Napa with his wife, and staying out late at nightclubs listening to live music.

A hospice nurse visits him once a week, at noon so he can sleep in. (A doctor, a social worker, and a chaplain are all on call 24/7.) The trio sit at his kitchen table and Hopkins strokes the hair on the back of his neck as they talk about his medications, his feeding tube, what to expect when he dies.

"She doesn't speak Latin to us," Hopkins said of the hospice nurse. Bartschenfeld nodded, saying, "They're very straightforward. They don't whitewash."

Frank conversations

The local hospice movement is not only pushing frank conversations, it's also trying to change the vocabulary doctors use. Rather than asking patients to make medical decisions in negative terms, such as "Do Not Resuscitate," they recommend "Allow Natural Death."

Dr. Monique Kuo, the medical director for Hospice of the Valley, framed a conversation this way, when doctors recommended moving one of her patients out of the ICU and focusing on palliative care. The patient's son was distraught.

"I don't want to kill my father," he told Kuo. "I don't want to be the one who decides if he lives or dies." Kuo explained that his role was not deciding what happened, but how.

"Your father is dying," she said. "His body has made this decision. You're helping him now to determine what kind of death he is going to have."

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A KINDER DEATH by April Dembosky

In San Jose hospitals, more people die in intensive care units than in most other regions in the United States. Across the country, the same number of people who want to die at home, die in a hospital. When I discovered these facts, I began exploring the local hospitals' culture around death. I talked to palliative care doctors and hospice staff and discovered the tension between medical professionals trained to save lives at any cost and medical professionals concerned with helping people die comfortably.

Death is a taboo topic that people are afraid to talk about and reporters seem reluctant to cover. But after my article came out, I discovered how restricted people feel by the taboo. I got dozens of phone calls and emails from people wanting to talk about their loved one who had died, their experience with hospice, or aggressive medical testing at the end of life. Over and over, they told me they didn't think anyone wanted to hear about their story, but they called me because they just wanted someone else to know the last words their husband said before he died, or that their mother passed in peace.

Then I heard from a chaplain at a nearby hospital who was counseling the family of an elderly woman in her last weeks of life. The woman had accepted her own death, but her children had not. The chaplain gave them the article I had written and it opened a whole level of communication within the family. The children began to discuss the impending death more frankly. They were able to hear and honor their mother's wishes.

I realized that this is the kind of impact I hope to have as a journalist - to help people start conversations they had long been avoiding.

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