

Conversations, large and small, between patient, loved ones, and caregivers, are turning points along the path to life's end. Sometimes awkward or grueling in their candor, they can offer an unexpected thread of hope through a labyrinth of loss. These end-of-life conversations can heal and bring a sense of control. Through dialogue, emotions are felt and worked through, unimaginable challenges are wrestled down to size, and the spirits can be raised. But too often the words don't come. Or they come too late. Or they pale beside the painful emotions of the moment. America is calling for death with dignity. We know that talking about this painful topic may well bring us peace and comfort. Yet too often we avoid the very end-of-life discussions that make possible dying well and coping with loss.

And it's no wonder: On the patient's side, there is embarrassment or fear or a sense of being overwhelmed. Physicians tiptoe around these conversations or struggle to find a way to convey hope when hope no longer means what we'd like it to mean. And loved ones try to "stay positive" or have no idea what to say. As a culture we are moving together toward two inevitable conclusions: 1) There is no way around the realities of death and dying, no matter how we try to avoid them. And 2) Conversations can play a vital role in helping move us closer to whatever awaits on the other side of our loss. Silence breeds separation, but by talking through our fears of death, hope and a sense of connectedness may replace avoidance, denial, and fear.

In doctors' offices, living rooms and town-hall meetings across the nation, people are learning to master a new vocabulary that will lead them out of the silence. As America's 80 million aging baby-boomers are about to discover, there are many steps to the process, from talking early about medical planning to coping with the illness and its treatment; from grappling with the physical and spiritual dimensions of impending death to mourning that death once it comes. Along the journey, these steps can be thwarted in all kinds of ways: strained family relations; feeling powerless in a health care universe of powerful others; denial; communication hampered by physical debilitation; even sudden death.

Yet even in the face of these obstacles, people can and do find ways to use conversation as a tool for coping and communicating their love and concern. And in so doing, they navigate the labyrinth with courage. Sometimes, the conversations that are part of early planning don't come easy. For Lynette Polian and her mother, Ethel, 84, the onset of Alzheimer's robbed them both of the opportunity to have those end-of-life conversations in the first place.

It first really hit Lynette one day in 1997. Lynette had just moved home from Los Angeles to care for her mom, thus becoming one of the more than 25 million Americans-the hidden heroes of America-who provide care for elderly or critically ill family members. She was reading some poems to her mother when she noticed Ethel was in tears.

"Why are you crying?" Lynette asked.

"I'm crying because I didn't have a mother," her mother replied.

"Yes, you did have a mother."

Ethel said, "Well, I did, but I never knew her."

Lynette was scared. "That's when I thought to myself, Oh, boy, we're in trouble here. I realized at that moment that this conversation was going to be all one-sided. The Alzheimer's was going to have its way with both of us. After all, meaningful communication requires a working memory."

Still, Lynette didn't give up. "I felt resignation, but I was resigning myself to the fact that I was going to cope with Alzheimer's as best I could."

It may have been too late to have the conversations with her mother that she wanted. But it wasn't too late to take control in other ways. Lynette got her mom into an adult day-care center. She fired Ethel's doctor and found another physician she felt she could talk to. She knew-and planned for-the kind of funeral and services that her mom, a devout Catholic, would like. And as Ethel's Alzheimer's worsened, her daughter got her hospice care.

"I knew Mom very well, but sometimes I still had to second-guess what her real wishes might be," said Lynette. "There were limitations, but I was lucky to have help and resources so I could do what I needed to do."

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Her ten-year Santa Clara University reunion for the class of '85 should have been a time of joy. But Teri Downey came to this one with very heavy heart. While her classmates happily shared their life's accomplishments, Teri had only the death of her beloved daughter, Samantha, on her mind and in her heart. The previous January, Samantha had succumbed just after her third birthday to a rare childhood cancer. Conversations with Samantha were a challenge because of her tender age. Yet Teri and her husband Steve managed to have other conversations-between themselves and with their health professionals-that ultimately lightened the load for everyone, including the dying girl.

As Samantha's illness worsened and metastasized to her lungs, Teri and Steve faced some gut-wrenching decisions. But by talking things through at each step of the way, they were able to agree on those nightmarish but unavoidable decisions faced by parents with dying children. "We had seen other couples whose kids had died and who were really messed up," she said. "We decided that Samantha was not going to suffer because Steve and I weren't on the same page, with one of us ready to stop curative treatments and the other not."

Another critical set of conversations that helped the parents and their daughter move through the dying process took place with an outstanding pediatric anesthesiologist. He called himself "Samantha's personal anesthesiologist." "He had a love for Samantha, too," Teri said. When Teri and Steve had to decide whether to intubate the child and put her on a ventilator, the doctor sat down with the couple. "He went over what the situation meant, all the pros and cons, and what he would do if she were his child," she said. They chose to get support from St. Elizabeth's Hospice, part of Catholic Healthcare West. The couple's daughter died at home, surrounded by loved ones. About two days before Samantha died, there was one more conversation. It took place while the girl was wearing an oxygen mask. She looked up at her father, then simply said, "I'm OK, Dad." And this is what Teri took from that last fleeting conversation: "Samantha got it. And she did her part in preparing us to lose her."

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Sometimes, when death comes suddenly or in a blur of violence, the end-of-life conversations simply cannot take place. Yet even in those cases, when a loved one is stolen away without warning, people can still manage to find a way to talk about their loss and go on living with hope in a world in which loss is inescapable. This happened to Ray Harbert. A World War II veteran

and recipient of a Purple Heart and a Bronze Star, Ray was one of 40 GIs in the first audience that Pope Pius XII held for American troops. While stationed in Europe in the 1940s, Ray learned of the birth of his daughter Cathi. Thirty-eight years later, in 1982, Ray received a different kind of news about Cathi. After having been missing for five days, her body had been found in a dumpster by a bag lady. Cathi had been murdered. "She was," Ray recalled, "the apple of my eye."

A year later to the day of Cathi's disappearance, Ray got more bad news. His son, Patrick, who had been deeply shaken by the death of his sister, had killed himself. Unlike many who lose loved ones, Ray never got to say goodbye to either of his children. There were none of the conversations we usually reserve for our final moments with someone we love. No forgive me, I love you, I'm sorry, good-bye. There was only a silence he would now be saddled with forever. "I felt all alone in this world," he said.

Still, Ray did not allow the silence to engulf him. Other conversations, sometimes with perfect strangers, helped fill the void, and reconnect him to the rest of the world. In a taxi ride he shared with the flight crew that had flown him to a business meeting shortly after Cathi's death, Ray found some comfort. The crew members were incredibly caring and supportive, he said. He realized what many dealing with the death of a loved one find out: Relief and refuge often come from the most surprising places.

"My own family," Ray said, "was too overwhelmed to provide much support." But his boss, Jack Duffy, spent time with him, and together they attended a special Mass for Cathi. His longtime friend, Bill Fields, also spent whole days talking the tragedy through with Ray. "Conversations," Ray said, "were the only way I could have gotten through this. Period."

These end-of-life conversations don't necessarily end at the end of life. For many who have lost loved ones, part of the healing process is a journey in its own right. And conversation has its place along that road as well.

One of the most common forms they take is through the act of giving of oneself, of taking one's pain and loss and deepened empathy and putting them to work in the service of others. Many of the more than 96,000 hospice volunteers in America today, for example, had their helping journeys launched by a personal loss.

That's what happened to Ray. After the murder of his daughter and the suicide of his son, Ray eventually began volunteering. A diabetic himself, Ray began to give his time as a speaker at diabetes centers. Just as those flight crew members in the taxi had opened up their hearts to a man whose life was wracked with pain, Ray now discovered the rewards of giving to others.

After her mother's death from Alzheimer's, Lynette Polian became actively involved as a board member with the adult day-care center where Ethel had been cared for in her final days. It was as if Lynette, even in the absence of her mom, was continuing to do battle-"the best she could"-with the illness that had taken Ethel away.

And sometimes, the conversations that live on after a death unfold on a new and higher plane. This happened to Teri Downey. Raised Catholic but not practicing her faith very much at the time Samantha died, Teri said the loss of her daughter became a catalyst for the renewal of her spirituality. Her church community also stepped up and provided her wonderful support. "The one good thing about Samantha's death," said Teri, "is that it reconnected me to my faith."

Teri's faith and experience with death also led her to become a hospice volunteer. She and Steve adopted two children and Teri would bring one of them along with her when she visited a dying woman over a period of months. Just seeing the infant, said Teri, seemed to ease the woman's suffering as her life gradually ebbed.

As the passing years and her new family help Teri move forward, she still holds Samantha's memory firmly in her heart. Most days, she lives by the words that speak to her from the little note attached to her refrigerator door:

"Life is easier than you think," it says in its own quiet and candid way. "All you have to do is accept the impossible, do without the indispensable, bear the intolerable, and be able to smile at anything."

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originally published in *Santa Clara Magazine*.

#### Resources:

Larson, D. G., & Tobin, D. R. (2000). End-of-life conversations: Evolving practice and theory. *Journal of the American Medical Association*, 284, 1573-1578.

*Handbook for Mortals: Guidance for People Facing Serious Illness*, by Joanne Lynn and Joan Harrold (Oxford Press, 1999)

*Peaceful Dying: The Step-by-Step Guide to Preserving Your Dignity, Your Choice, and Your Inner Peace at the End of Life*, by Daniel Tobin (Perseus, 1999)

*Care of the Dying Child*, edited by Anne Goldman (Oxford University Press, 1998) *Living with Grief After Sudden Loss: Suicide, Homicide, Accident, Heart Attack, Stroke*, Ken Doka, editor (Taylor and Francis, 1996)

#### Websites:

The Markkula Center for Applied Ethics at Santa Clara University  
<http://www.scu.edu/ethics/publications/iie/v14n1/toughtalk.html>

The Finding Our Way: Living With Dying in America newspaper series [www.findingourway.net](http://www.findingourway.net)

Bereaved Parents of the USA [www.bereavedparentsusa.org](http://www.bereavedparentsusa.org)

Children's International Project on Palliative/Hospice Services

(ChIPPS), National Hospice and Palliative Care Organization <http://www.nhpco.org>

The Candlelighters Childhood Cancer Foundation <http://www.candlelighters.org>

National Hospice and Palliative Care Organization [www.nhpco.org](http://www.nhpco.org): Offers a hospice database and provides statistical and educational material about hospice care. Or call the toll-free HelpLine at (800) 658-8898 to find a hospice near you.

Growth House: Offers links to many bereavement sites, including those specializing in diversity. [www.growthhouse.org](http://www.growthhouse.org)

American Association of Retired Persons - Widowed Persons Service  
[www.aarp.org/griefandloss/](http://www.aarp.org/griefandloss/)