

October 6, 2005

## Farewell, With Love and Instructions

## By LIZETTE ALVAREZ

MELANIE SOVERN, a 15-year-old with thick black hair and forgiving eyes, often feels her mother's tug when she is alone in her room after school. It is during those moments that she will reach for the videotape, slide it into the machine and settle back into her mother's words, the richness of her voice, the solace of her smile.

"Try not to wear heels," Melanie's mother, Gail Sovern, says on the tape. "Dyeing your hair is O.K. A little pink or purple is good," her mother continues, and "ear piercing is O.K., at 11 or 12." Fast-forward and there is Gail, then 39, in her bathrobe, laughing and dancing to "Tie a Yellow Ribbon," with Melanie, then 5, clinging to one arm, and her sister, Lindsay, 3, snuggled into the other.

Mrs. Sovern died 10 years ago of breast cancer. Since then, much has happened. The girls' father, Jeff, has remarried and had another child; Lindsay, now 13, has traveled from the perils of potty training to the mortification of a school uniform; and Melanie, 15, is racing toward college.

"If it weren't for the videos and pictures, we probably wouldn't know much about her," said Lindsay, an eighth grader at Kew Forest School in Queens.

"Because memories can be there, and not be there," Melanie said, quickly finishing her sister's thought. "This is a permanent memory that will never erase."

Hoping to nurture their children from afar and assuage the dread of leaving a child too soon, a small but growing number of terminally ill parents are painstakingly leaving behind more tangible links: audiotapes, videotapes, letters, cards and gifts that children can use to bolster memories and use as a guiding hand.

The tapes bear messages of love and remembrance: the dress a daughter wore on her first day of kindergarten, the thrill of a trip to Yankee Stadium, a son's jitters before a first piano recital. The letters riff on parents' life stories, their hopes for their children and the life lessons they wish to impart. Some parents choose gifts or cards for future birthdays or Christmas celebrations. One mother created a tape to be given to her son on his wedding day, if and when that occasion arrives. One father left written messages behind paintings, a surprise that his children stumbled across a year after his death.

Through these things, dying parents bequeath courage, laughter, a semblance of companionship and even a guiding hand, therapists and spouses said. The keepsakes help crowd out the searing tableaux of death with reminders of how Mom or Dad sounded, moved and thought about life.

For years oncologists and therapists have believed that leaving a "heart will," as one therapist calls it, goes a long way toward easing the emotional suffering of dying people and their families. It is something some professionals carefully, sometimes tentatively, encourage terminally ill patients to do. But doctors have begun studying the benefits in medical trials only recently.

"It's profoundly beneficial for the kids," said Dr. William S. Breitbart, the chief of psychiatry service at Memorial Sloan Kettering Cancer Center in New York City. "But it is rare. Almost everyone thinks about it, but it will get delayed or put off. I think it's very difficult to do this because it really demands a confrontation, an admission, a real admission that you are dying, and that is very hard for most people. What is at play is this struggle in their mind between hope and despair."

By the time many patients, particularly young parents, come to terms with death, they often feel too ill to write a letter or look too sick to want to record themselves. Others may feel they lack the eloquence or wisdom to say anything meaningful.

"It takes on such incredible significance, a final message, it has to be said perfectly," Dr. Breitbart said.

But according to children, any message, any memory, is meaningful, no matter how trite it may sound to an adult.

"It doesn't have to be the most profound life lesson," Melanie said as she spoke about the video recordings of her mother. "It's the day-to-day things."

Dr. Harvey Chochinov, the director of the Manitoba Palliative Care Research Unit in Winnipeg, Manitoba, and a psychiatry professor at the University of Manitoba, said that leaving a spoken legacy is important to both patients and family members. He is leading an international clinical trial, supported by the National Institutes of Health of the United States, to explore the impact of "dignity therapy" as death nears. The results of a pilot trial were published in August in the Journal of Clinical Oncology.

As part of the trial dying patients held extended conversations with therapists about their lives, the things they wanted to say before they died, their dreams for their loved ones. Those discussions were recorded, transcribed, edited, reviewed by the patients and then passed on to relatives.

Most patients said it heightened their sense of purpose and gave meaning to their lives. Family members cherished the transcripts.

Dr. Chochinov said he hopes the published results will encourage widespread use of therapeutic approaches like dignity therapy.

Donna Schuurman, the director of the Dougy Center for Grieving Children and Families in Portland, Ore., said Western society to a large degree is "death denying," a culture that values "moving on" rather than remembering. "People don't know how to do it," she said.

In families without heart wills, children often hunt for some remnant of a deceased parent. For one boy that meant saving his mother's voice on an answering machine tape. "They have an incredible desire to know who that person was," Ms. Schuurman said. "What the children are left with, what the family is left with, are memories."

Every birthday and Christmas for the past three years, Lindsey Frilot, 11, of Gresham, Ore., has set aside one present to be opened last. The present is from her mother, Lisa, who died of cancer three years ago but managed with the help of her own mother to choose presents and cards from her hospital bed for Lindsey until she reaches 21.

On her ninth birthday Lindsey received a brown jewelry box with a card that read: "For a sweet daughter. Once upon a time a special wish came true and life was blessed forever with the one and only you."

A year later she unwrapped a charm bracelet, and on her 11th birthday she was presented with her mother's pearl necklace. Every Christmas she opens a new Willow Tree Angel from a line of figurines meant to heal wounds and foster closeness. They all sit atop the mantle.

"She picked them out," said Lindsey, who often talks to her mother at night and twice a year releases balloons with a message for her. "It makes me feel like she is there with me more."

"I tell her about my day and my problems," she said.

The four Coughlin children, now college age, said their mother, Dorothy, and dying father, Tim, took pains to leave them with links to him: he wrote them a letter and after his death a statute of St. Francis arrived for his garden behind the family's home in Portland, Ore.

A year later the children discovered a surprise from their father, messages on the backs of paintings.

Tim Coughlin, 42, said in his letter 13 years ago that dying was a natural part of life.

"As Daddy died, he saw himself like a dying or dead tree in the forest standing," Mr. Coughlin wrote, going on to describe how he would shelter birds and revel in being bleached by the sun and the wind.

Mrs. Coughlin said the children cherish memories of their father, in part because they learned to celebrate his life rather than mourn his death. "He didn't die," she said. "He lived the experience of dying."

Joel Siegel, the film critic for ABC's "Good Morning America," who has cancer, wrote a 2003 book titled "Lessons for Dylan" for his son, now 7. It is a memoir of sorts that ends with advice: "College is the only time in your life when you'll have time to waste," he wrote. "Waste some."

A chapter titled "Where Do Babies Come From?" provides this three-word reply: "Ask your mother."

"There is an awful lot we can offer our kids," said Mr. Siegel, who is now undergoing chemotherapy again. "The most important things are pieces of us."

Earlier this year the writings of a woman from Wales captivated the British public after her death from breast cancer when a newspaper published her detail-laden "Mummy Manual," written for her husband and 7-year-old daughter, Ffion.

"Bath and hair every other night, at least. No child of mine to be smelly," wrote Helen Harcombe, 28, in the hand-scrawled manual, later printed in The Daily Mail. "Ensure hair is tied back for school. Neat parting, no bump" and "no straggly bits."

The list, often without the luxury of complete punctuation, goes on: "Keep her swimming. V important."

"Before long put lock on bathroom door she will appreciate that as she gets older."

"Dress her trendily outside of school boot-cut jeans, trendy boots, go to tidy shops not Woolworths or Oxfam!"

And, above all, "Keep in touch with Fi's godparents + my friends, especially Mom + Dad or I'll haunt you."

Copyright 2006The New York Times Company | Home | Privacy Policy | Search | Corrections | XML | Help | Contact Us | Work for Us | Site Map | Back to Top