Heartfelt messages, gifts help children hold onto their parents long after their passing

Julie Keefe THE NEW YORK TIMES

Every Christmas, Lindsey Frilot, 11, unwraps an angel from her mom, who died three years ago.

LESSONS before dying

By Lizette Alvarez
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NEW YORK— 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 OK. A little pink or purple is good," her mother continues, and "ear piercing is OK, 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.

Gail 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, N.Y.

"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."

These days a growing number of terminally ill parents are leaving behind audiotapes, videotapes, letters, cards and gifts. These items help dying parents, particularly when young children are involved, bear the feeling that they are leaving the job undone, handing down only vague memories or searing tableaus of death unfolding. "Who is going to tell them to wipe their noses or stay clean?" asked Peggy Anne Murphy, program coordinator for children's services at CancerCare in New York, a nonprofit national support group. "Who will open their knapsack?"

The hope imbued in these final mementos is to bolster fragile memories and foster a connection beyond death. 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

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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.

Beryl Southall, the bereavement coordinator at Hospice Austin, videotaped her 100-year-old grandmother, Laura Matthews, before she passed away five years ago. "She was the matriarch of our family. We asked her to tell us about her life. We asked her to give us something to hold onto and to give us wisdom. It was a way for our family to honor her," she said.

Southall said "heart wills," as they're sometimes called, are nothing new. "It's been the passing of stories from one generation to the next. When we couldn't do it electronically, we talked and passed on stories," she said.

To families, with love

For years oncologists and therapists have believed that leaving these remembrances 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 Breitbart, the chief of psychiatry service at Memorial Sloan Kettering Cancer Center in New York. "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."

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 might 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," Breitbart said.

But according to children, any message, any memory, is meaningful, no matter how trite it might 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, 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. 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," Schuurman said. "What the children are left with, what the family is left with, are memories."

A present for Lindsey

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 mantel.

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

"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 statue 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.

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 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."

Staff writer Ricardo Gándara contributed to this story.

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Melanie Sovern, 15, seated, and sister Lindsay Sovern, 13, can still hear and see their mother in videotapes she left for them. Gail Sovern, in framed picture, died 10 years ago of breast cancer. The sisters say the taped messages help them through the rough times when they miss their mom the most.