



Giving a Voice to Sorrow

Personal Responses to Death and Mourning

by Ilana Harlow and Steve Zeitlin

Adapted from *Giving a Voice to Sorrow: Personal Responses to Death and Mourning* (New York: Viking Penguin 2001) for the Heritage to Health: Harnessing the Power of the Arts for End-of-Life Tool Kit. (Used with permission.)

Table of Contents

1. Introduction
 - a. A Buddhist Tale
 - b. Inward and Outward Expressions of Grief
 - c. Changes in the Way We Die
 - d. Storytelling
 - e. Death and Place
 - f. Conclusion
2. Dying in Character: A Six-Year-Old Girl with Leukemia Designs Her Own Death
3. Making Art with the Dying: A Hospice Worker's Perspective by Katherine Blossom
4. Creating a Home Altar
5. Still Born Funeral told by Susan Knightly
6. The Added Meaning of Coincidence After Death about Judith Obodov Hardin adapted from Marilyn Webb's *The Good Death*
7. Daughters Craft a Coffin for their Father told by Peggy King-Jorde
8. Making a Memorial Quilt by Sheryl Mullane-Corvi and Kathleen Doyle
9. When Death is Disenfranchised: Private Rituals of Grief: The Beau Geste adapted from Erika Brady
10. Public Evidence of a Private Memory - One Hundred Smooth Stones for Grandfather told by Arlan Huang

1. Introduction

a. A Buddhist Tale

In a Buddhist tale of death and mourning, a wealthy man of the Savatthi country in India married a young girl, Kiságotamí. In time, she gave birth to a son. When the boy was able to walk by himself he died. The young girl, in her love for him, carried the dead child clasped to her

bosom from house to house asking if any one would give her some medicine for it. When the neighbors saw this, they said, "Is the girl mad, that she carries about on her breast the dead body of her son?"

In desperation, she visited a holy man and asked him to cure her son. He said, "I need a handful of mustard-seed." The girl promised to find some. "But," he continued, "I require some mustard-seed taken from a house where no one has died." She traveled from house to house carrying the dead body of her child but she could find no house that had not suffered great loss. "The living are few, but the dead are many," she was told. One said, "I have lost a son;" another, "I have lost my parents;" another, "I have lost my husband."

At last, not being able to find a single home where no one had lost a son or a parent, she began to think, "This is a heavy task that I am engaged in. I am not the only one whose son is dead. All over Savatthi children are dying, parents are dying." Thinking thus, she summoned up resolution and left her son's body in the forest.

In this traditional tale, found in many different versions around the world, a young woman confronted with unfathomable loss comes to accept the human condition. Through her futile quest for a home that had never known sorrow, she was inducted into a community of mourners, in whose midst she lived; she encountered neighbors who carried on despite devastating losses. She thus learned that it was indeed possible to endure, and that such endurance is the way of the world.

The young woman's search evoked stories from her neighbors about the loss of loved ones. In this way the bereft mother was provided with a kind of grief support group whose members shared stories about their experiences with loss. This essay and the examples that follow, too, are a sharing of stories. They present a variety of creative ways through which people have responded to the imminent loss of their own lives or to the loss of loved ones. *Giving a Voice to Sorrow* explores how contemporary men, women and children have used storytelling, ritual, and memorial art to cope with death and to celebrate life. It documents outward expressions of inner struggles.

b. Inward and Outward Expressions of Grief

Over the past half century, a number of scholars have sought to chronicle the inward processes that individuals go through as they experience old age and death. In 1950, psychoanalyst Erik Erikson wrote that the key issue for people at the end of life is 'ego integrity vs. despair': acceptance of their own life as they lived it vs. despair over not having time or opportunity to try out alternate paths.

In 1963, psychiatrist Robert Butler introduced the concept of life review. He suggested that all older people engage in a mental process of looking back over their lives. He argued that such reminiscence, often misinterpreted as a form of senility, is a creative process through which people make sense of their lives in the face of death. Often they reflect upon past conflicts and

are able to achieve resolution, a sense of integration, and serenity before they leave this world.

In 1969, Elisabeth Kübler-Ross suggested that most people, upon being diagnosed with a terminal condition, experience five psychological states -- denial, anger, bargaining, depression, and acceptance -- as they confront their deaths. Those confronting the deaths of loved ones often experience the same psychological reactions; the folktale of Kiságotamí aptly illustrates a grieving woman's progression from denial (seeking medicine for a dead child) to acceptance (realizing the universality of death).

This essay and the examples that follow complements the work of these pioneering thinkers by chronicling contemporary *outward* expressions of loss, love and longing which people craft in response to death. Many older, traditional responses to death involve the creative impulse through stories, music, art and rituals connected to funerary rites. In our time, in addition to these traditions, and sometimes in lieu of them, it has become increasingly common to find mourners and the terminally ill engaged in a personal -- and often shared -- creative act.

"One does not possess one's past as one possesses a thing one can hold in one's hand, inspecting every side of it; in order possess it," wrote John Paul Sartre. "I must bind it into existence with a project." Increasingly, the dying and the bereaved engage in creative personal projects that bring a shared past into existence with a story, a ritual, or a work of art. Creativity can help people to transform and even transcend difficult situations. Commemorative art, rituals and narratives often capture the essence of the person who has died and serve to evoke that person's presence among the living. Those who no longer walk the earth are spirit and dust. We can only know them through their creations, and through the rituals, stories and art that those left behind create about them.

We hope this essay and the dramatic examples that follow may serve as inspiration to those who are just beginning similar journeys. This is not a "how to" for dying and mourning. There is no "right way" to mourn or to die, no single way to enact one's sorrow. Death presents us all with an impossible situation, and there is no way to get it exactly right.

Eventually, the emotional responses of sadness, horror and anger over death can make way for creative responses which evoke the human spirit, as people struggle to endure, despite their grief. As we have explored creative responses to death, outward expressions of inner lives, we have been privileged to gain glimpses into the hearts, minds, and souls of some extraordinary individuals. We, like the young mother in the tale that opened this chapter, have visited many houses which have known sorrow. Following this essay, we share some of the stories, rituals and memorials that have saddened and inspired us. However, like the residents of Savatthi country, we can provide no mustard seed.

c. Changes in the Way We Die

The baby boom generation, writes Marilyn Webb in *The Good Death*, has transformed every

stage of the life cycle. It changed the freedom with which we have sex, the way we marry, grow old, and it is in the process of revamping the way we die. A contemporary generation of Americans is making personal creativity an increasingly common part of the process.

Formal religion has often governed our responses towards death, dictating the ways we are buried, the ways we try to comfort the bereaved, and the ways in which we mourn and memorialize loved ones. Such traditions tell us how to act and what to say at times when we otherwise might not know what to do or say. They provide comfort. They are responses to death which have been used repeatedly by members of our respective communities whenever necessary.

Sometimes, however, traditional responses do not satisfy. People who are not affiliated with a religious community often create secular rituals to mark someone's passing. As Dan Silverman commented about the rituals surrounding the death of a teenager in his own community, "These are ceremonies that we've created ourselves. They're not anybody's liturgy or anybody else's ritual. They're expressions of our own spirituality-- without the need for somebody else's formalistic rules. It feels much more real to those of us who are not interested in anybody else's ceremony, to have created our own."

Even people who are affiliated with a religious community often feel the need for more personal responses in addition to the formal institutional rites. Tradition is not only something we receive but something we transmit, something we create. Maintaining tradition, adapting it to the times in which we live, is a creative act. Sometimes people creatively adopt and adapt traditions from religions other than their own. Yet, the growing number of expressive responses to death cannot be looked at only as a trend--each one is a personal response to a struggle in the consciousness of each bereaved individual.

There are some kinds of losses that religious institutions or society at large have not formally recognized, and therefore have not devised formal ways of mourning for them. Grief over a miscarriage, a stillborn baby, the death of an ex-spouse, unmarried partner, or an extra-marital lover have all been defined by Ken Doka as instances of "disenfranchised grief." Such losses are sometimes addressed through private, personal rituals

The grief of those affected by the death of newborn babies or unmarried partners, often is not validated by our social systems. Many people attempt to comfort women who have had miscarriages by saying, "You'll have another baby," or "It's for the best. The baby wouldn't have been healthy." These inadequate responses do not acknowledge the reality of loss. In recent years people have been finding ways to validate disenfranchised grief and address it through the creation of new rituals. Today, even many hospitals have institutionalized rituals which are enacted in response to the death of stillborns and newborns.

The new creativity in response to death has also rediscovered some of the Victorian death customs considered so morbid a generation ago. These include the creation of mourning quilts made out of clothing of the deceased, decorated caskets, and formal photographs of the dead.

Interestingly, a relatively recent phenomenon - the hospice movement, has helped to revive another death rite from the past - the formal death-bed scene in which the dying assemble their loved ones around them.

Hospice focusses on palliative care, or pain relief, rather than on curing the terminally ill or prolonging their lives. Therefore, those in hospice care often die at home amidst friends and family rather than amidst a tangle of tubing from life support machinery in a hospital. Phillip Aries has pointed out that hospitals transformed death from a social event to a technological one. Hospice is helping the dying and their loved ones to reclaim death as a rite of passage.

The changes in the way we die are especially pronounced in the way a new generation is often choosing to be cremated rather than buried. As funeral director and poet Thomas Lynch notes in an interview with us:

In thirty years we've gone from a country that cremates three to four percent of its dead to a country that cremates thirty percent of the dead. This is a radical shift, and it's completely attached to the secularization of the culture. In most of Western religious thought fire is punitive – when you were in trouble with God you burned in hell. For people in Western cultures to burn their dead is not the same as doing it in Eastern cultures where fire is purifying and releasing. This is why in the East they burn, in the west they bury. But in the West, in one generation we've gone from a culture that buries to a culture that burns.

It's not right or wrong to bury, or right or wrong to burn – it's how we do it. It's not a question of what is done but how it's done. Our culture doesn't place any ceremonial value in cremation, whereas in Calcutta cremation is public and it's attended by a lot of symbolic and ritualized behavior. Fire is brought by the first-born child from the home to ignite the fire. But here cremation is often minimalization, disappearance. So people never say, "Please cremate me," they say, "Just cremate me." The emphasis is on the "just part. Cremation helps keep us mobile – when you cremate someone you end up with ashes, unlike when you bury them. How do we consider those remnants? Are they leftovers? Are they icons? Are they relics? What are they? Everybody gets to decide that for themselves.

It used to be that people would cremate their dead and then put the ashes in a columbarium or put them in a family plot, but now cremation makes the dead mobile. And it makes them divisible. You can't divide a body but you can divide up the ashes. A son will say, "Dad like to fish in the river; he'd have liked to be scattered there." But Mom says, "Yeah, but I'd like to have dad buried with me." And the daughter who lives in California says, "Yeah, but what about me? So she'll take some in a locket, the son will scatter some up where and his dad fished, and Mom will keep some at home to be buried with her when she dies. Those are creative responses to mortality.

We sometimes speak of the desire for immortality. Yet most of us, contemplating our own

deaths, are not concerned with the way we may or may not be recalled in five hundred years on the tongues of strangers. We are concerned with leaving a mark on the next generation, on our equally mortal children and grandchildren. We desire to have our own lives woven into theirs. When death spirits away a member of society, those who remain must figure out ways to maintain their relationships with the departed, to integrate them into their lives. Simple gestures such as a reminiscence or the commemoration of a birthday or anniversary of death, can give us the measure of immortality we need; not life everlasting but what the poet Wordsworth called "intimations of immortality." Some cultures put forth the belief that a person is not really dead until the last person who remembers the departed is also gone. For most of us, what matters and what is sufficient is to know that we will be recalled in living memory -- in what anthropologist Margaret Mead called the human unit of time, "the space between a grandfather's memory of his own childhood and a grandson's knowledge of those memories as he heard about them."

d. Storytelling

At Temple Beth Shalom, in Hastings, New York, Rabbi Edward Schechter describes his memorial services as the inauguration of memory. "Somebody's life could be ninety years," Rabbi Schechter told us. "but you have to sum up their life in five minutes." It's his responsibility to get the stories flowing. "You have to capture a person just right. You know how you take fine crystal glass, and you plink it, and it should sound like a bell. That clear. That's how you want it to be. You want to capture a person that perfectly. Sometimes I stay up all night thinking of the right story to make that pure sound. You want that to be just right."

When Reverend Sydney Wilde Nugent, a Unitarian minister in Washington, D.C. first sits down with bereaved families, the mourners often are in a state of shock. She works with them until the anger, memories, guilt and pain find expression and coalesce gradually into a set of ideas for her sermon. "What is your fondest memory?" she asks them. "If I can get that out of them and they begin to loosen that tight, closed mourning, they begin to realize that life goes on. They remember their mom and dad or their son. Particularly if you can get them laughing then it's not so terrible. It doesn't diminish their grief, it lets them handle it -- it's still grief."

"For example, this one family talked about a rubber snake. It would turn up in the sugar bowl or the kids would hide it and then the mother would find it, and you wouldn't hear anything about it for awhile and then it would show up in someone's shoe three days later. They told this tale with great relish. And then the two brothers got into an argument about whatever happened to the snake, and one of them maintained that he still had it, and the other -- 'No, no, it's a different snake!' It really loosened them up, and it gave a beautiful picture of this woman who had died."

The dead are vulnerable to misrepresentation, since they are, as Maura Spiegel and Richard Tristman write, "unable to enact their uniqueness by themselves." They can no longer speak for themselves; their memories, who they were, and in some sense, who they continue to be, is now in our hands, the hands of the living. When those close to us die, we are charged with

remembering. And stories are the tools of memory. They can capture the essence of a life and make it portable. The rhetorical device of 'story' provides a way to preserve and recall mannerisms, foibles, grandeur and courage.

In subtle but marked ways, the stories told after a person dies are different from those told when he or she was alive. The stories become charged symbols of a person's life. Telling them often becomes a ritual of remembrance. A few episodes have to stand for a complex individual who is no longer creating new episodes and stories.

When we tell a story about someone who has died, we remember them as alive, engaging actively in human activities. But our language, writes folklorist Kelly Taylor, has a subtle way of reminding us that the subject of the story is dead. "In English a dead person is properly referred to in the past tense. This subtle differentiation is a rule of which all native speakers are aware. That awareness often becomes acute the first time one must speak of someone in terms of 'was' and 'had' instead of 'is' and 'has.'"

The stories told at memorials are not necessarily the first stories told about a death. With our death, every one of us writes our own "death story." The details of our last days and hours will be focused on and told many times right after death. The death story will include our last words, details about the disease, or accident, or uneventful last minutes, and the exact time of death. The first question asked when a loved one dies is, "How did it happen?" Whether the person died peacefully in bed, or in a gruesome car crash, we want to know the details, the moment by moment chronology. We want to hear and to tell about the death in slow motion. Witnesses to the death may be asked to tell the story again and again. . . .

In one example of deathbed humor, Lynn Erdman, R.N. director of Presbyterian Hospital's Cancer Center in Charlotte, North Carolina tells of a woman who was dying "a slow but not painful death," sliding in and out of consciousness. The woman's two daughters were sitting patiently by her bedside day and night waiting for their mother to die. Several days later, one of them poked the other in the ribs and whispered, "How long do you think Mom will last?" Suddenly, Mom opened her eyes, looked at her two daughters at the foot of the bed, and declared, "A watched pot never boils. . . ."

Dr. Kenneth Goldstein, who was a well-loved folklore professor at the University of Pennsylvania, once described the storytelling at his father's funeral. He had returned to his parents' home in Brooklyn to "sit shiva," the traditional seven day Jewish mourning period. As a folklorist he found himself observing how the stories told among family and friends changed over the seven days. A period of speechless grief gave way to stories of his father as a righteous, saint-like man; later they changed to stories of his father as an ordinary man, as "everyman"; by the end, stories were told of his father as a trickster, a shrewd and funny man, good and bad by turns.

Goldstein compared this personal experience with the behavior he observed while conducting fieldwork at Irish wakes. "It always began the same way. As the mourners filed into the house

where the man was laid out during the wake they would always tell the family, "You're not going to have to worry about where he's going, St. Peter's going to welcome him in." Of course, before the wake was over, he was viewed as a mere mortal once again. The mourners reverted back to their role as fellow tricksters, placing a pipe in the dead man's mouth, or dealing him a hand in a game of cards."

Folklorist Kelly S. Taylor coined the term, "the storytelling wake" to describe situations where mourners gather to tell stories about the dead, particularly in the absence of established ritual. She proposes that these sessions, often initiated by the clergy at memorial services, but continuing informally among family and friends, are an exercise in reordering experience. She suggests that the deceased passes from a profane realm of immediate experience to the more sacred realm of memory. Storytelling can serve as a means by which the disordered emotions surrounding grief can be sorted into an acceptance of loss."

At informal storytelling wakes, an image of the dead often emerges which is broader in scope than the one in any single individual's mind; tales from different times and different people in one's life help reconstruct a "person of memory" who exists not in the everyday world, but the world of remembrance. . . The anthropologist Barbara Myerhoff coined the term *re-membering*, to call attention "to the reaggregation of members, the figures who belong to one's life story, one's own prior selves, as well as significant others who are part of the story."

e. Death and Place

We want to be remembered over time. And each of us will be remembered particularly at certain times of the year. People also are remembered at certain places which were associated with them in their lives or which become associated with them in their deaths. People even want to die in particular places.

In the city of Benares, India, funeral pyres line the banks of the Ganges river. Benares is the City of Shiva - the great Lord of Death and Destruction who dances over the city and swoops up souls. Devoted Hindus long to fall into his arms at death. They come to Benares to die with purses of rupees which they have saved for their funeral pyres. After they are cremated, their ashes will be scattered in the Ganges. In a South Asian neighborhood in Queens, New York, you can buy sealed copper vessels of water from the Ganges. The water is to be sprinkled on the dead who die away from the sacred place, to purify them before cremation.

Place matters. Sometimes the bodies of Hindus, as well as of members of other immigrant communities, are shipped back to the native land for cremation or burial. The bodies of Jews are sometimes flown to Israel for burial in the Holy Land. Jews buried in the diaspora often have a bag of soil from the land of Israel placed in their coffin. . .

The body is the place where we live, and dying is about leaving that place. It is the site of experience. It is our home and our coffin. As the Bosnian writer Semezdin Mehmedinović put it, we inhabit "the space of our own mortality." Often, we think of our cherished rooms and homes

as extensions of ourselves -- a part of ourselves made of more durable materials that will extend beyond our lifetimes. This is where we often want to find ourselves at the moment of death. An increasing number of Americans want to die at home -- a place where they are surrounded by their lives.

The artist C Bangs talks about moving her father's hospital bed into his study. "He felt very good in his study," she told us, "because he was surrounded by his books, by the awards he had received, and his work, and who he was. They had pictures on the wall in the bedroom, but it was just a bedroom. In the study, he felt grounded -- he was surrounded by his life. Every time that he went into the hospital there was a dramatic decline and then he would come back home to his study and he would spring back."

When a person no longer inhabits the body, a place must be found for the remains. The deceased and their loved ones sometimes collaborate on this creative choice; in order to decide, both need to determine what the life in question stood for, what characteristics defined that life, and match them with an appropriate place in the environment.

Karen Anderson told us, "My husband Dole traveled all his life, so we thought it was most appropriate to scatter his ashes at sea -- because the sea touches all the places he lived and loved." When we die, those who loved us want a place where they can come visit. When someone is lost at sea, people bring flowers to the seaside; they want to get as close as possible. They approach the place where it seems the souls of the dead must hover.

A family story told by Toby Blum-Dobkin illustrates the importance of the knowledge that a marker will be erected to one's memory on one's gravesite and the knowledge that mourners will have a place to visit. For Toby's grandfather Boris Blum, a name on a tombstone was not something to take for granted. His grandparents were killed in a pogrom, a violent anti-semitic attack, in the Ukraine. His parents perished in the Holocaust. A survivor of the Warsaw ghetto, and the death camps of Majdanek, Buchenwald, and Dachau, he had witnessed piles of corpses taken to the crematoria and burned. Once, a doctor conducting a medical history asked him to name any fatal diseases that had taken members of his family. He had no answer for the doctor, since no family member in living memory had died a natural death. If he were given a funeral and a tombstone, he would be the first member of his family in three generations to do so. As he put it, it was "like being published."

Boris Blum died suddenly of a heart attack on Passover in 1985. His family worked hard designing the tombstone that meant so much to him, inscribing it not only with the dates of his birth and death, but the date of his liberation from the camps. On it, they placed a memorial to all the other members of the family who had died without a tombstone. At the head of the stone are words taken from the Talmud, an ancient Jewish text, which are appropriate for a printer and a printer's son: "The scrolls burn, but the letters rise."

Many of the people we spoke to established a place where, they believed, the spirit of the dead resided, even if their physical remains were elsewhere. When Barbara Kirshenblatt-Gimblet's

sister died, her nephew still sensed the presence of his mother, who had been a piano teacher, in the house. "Where is she?" asked the grown-ups.

"On Middle C," she answered.

We believe that part of the meaning of our lives is preserved if our physical remains are near the places where we have lived or that we have loved. The human spirit, aware of its own transience, seeks the permanence of places, and often the permanence of stone. Places of Remembrance, like stories and rituals, bridge life and death.

f. Conclusion

"Our greatest desire," writes Daniel Taylor, "greater even than the desire for happiness is that our lives mean something. This desire for meaning is the originating impulse of story." The gossamer of story stretches delicately across the chasm between life and death. Families and friends work on the bridging the gap from both sides; the dying review their own lives, pass on their own stories, and shape their words and actions to fashion a suitable ending for their life story; on the other side loved ones select and embellish the stories to remember their dead; they stumble upon and interpret coincidences and dream dreams in which the dead communicate with them across the divide. Made of dreams, happenstance and memory, the span of story is hardly firm enough to walk across. But as human beings it is a way -- the only way we have -- of surviving our deaths, and of carrying our loved ones with us wherever we go.

A story. At memorials and shiva houses, Rabbi Eli Rubenstein from Toronto employs an apocryphal tale about the famous violinist Itzhak Perlman. Perlman was playing a concert, he tells, when there was a loud pop -- a string on his violin snapped. His playing came to an abrupt halt. The crowd expected the violinist to disappear backstage to restring his instrument. Instead he motioned to the conductor to begin the movement again. Then, through sheer genius and determination, he proceeded to play the entire length of the piece on only three strings. The audience was stunned by his virtuoso performance. They rose in spontaneous and continuous applause.

He silenced them with one simple sentence: The challenge in life is to make music from what remains.

Exemplars

2. Dying in Character: A Six-Year-Old Girl with Leukemia Designs Her Own Death told by Elena Lister

Liza Lister was diagnosed with leukemia on the eve of her fourth birthday and died twelve

days after her sixth birthday.

When Liza was admitted into the hospital for pain control [not long before her 6th birthday], we knew there was nothing else the medical establishment could offer her. As we awaited the biopsy results both Phil and myself knew it was going to be bad news; before the diagnosis came, we knew. So we had this feeling that it was going to be our worst fear. And her bone marrow transplant doctor came into her room and told her that the leukemia was back. And I was surprised Lizie didn't ask anything at that point. She nodded. I saw that she took it in.

It was my turn to stay with her in the hospital that night. Phil and I took turns. And we always did a lot of Nickelodeon in the evening and I think probably we had rented a movie. And then we were getting ready for bed and were in the bathroom. And she was brushing her teeth, doing a last potty stop, things like that. And I think I actually was kneeling down next to her helping her with her clothes because her skin was very sensitive.

And that's when she said, "Am I always going to have my leukemia?"

So I remember thinking, "Okay, here we go."

And she must have been sitting and working though this that afternoon.

And I said, "Yeah, we think so."

Then she said, "Am I gonna die from my leukemia?"

I said, "Yeah, we think so."

And then she said, "Am I gonna die soon?"

And I said, "We don't know when."

And she said, "Well, will I get to be a teenager?"

And I said, "I don't think so."

"Will I get to be a Mommy?"

"I don't think so."

That broke my heart because she would have been a great Mom.

"Will I get to have my cow?" Liza wanted a live cow in our New York City apartment.

And at each of these questions I said, "I don't think so."

At that point I was down on my knees. We were eye to eye and she was leaning on my shoulder and I was holding her, chest to chest. And she paused for a minute and was taking it all in.

And then she said, "I know how I want to die."

It just totally blew me away. And my guess is that she'd thought about it before, actually. We'd had one or two other conversations about dying, but I think she must have been doing a lot more thinking than she told us about.

"I want to die on your lap. I want to have my lullaby tape on. I was born to listen to that music and I want to die to it."

And then she said, "I want you to die with me."

I remember thinking at the time, "I think I will."

I could tell she was really picturing this scene because she immediately said, "No, no, no, no. I want you to die right after me. I want you to die right after me so you can be with me when I die."

So she really was imagining the scene. She wanted me to be intact, able to be a giving presence while she actually died; then I'd follow her. When she was four and a half she said she didn't want to die cause she didn't want to be alone. And, I mean, who does? It's the ultimate aloneness. So I think that was just in keeping with the same line of thinking. So she set a stage. Later on there were elaborations, "I want to die at home. What will dying be like? How will I know when I'm actually dying?"

Her lullaby tape was called "Til Their Eyes Shine." It's a wonderful collection of lullabies from people like Carole King and James Taylor. She listened to it from early infancy. And at the hospital she always wanted it on at bedtime. We'd put it on and she would quietly go to sleep. So it was a major comfort to her and we never went to the hospital without her tape recorder and that tape. And eventually it got worn out from listening to it so much. And we went on this mad scramble to find it again which was not easy at all. And then we

taped a few copies of it. So for her the tape had some elemental connection to us and comfort and safety.

That night, after our conversation in the bathroom, she wanted to sleep on me. And I remember feeling her heart beating against me, and feeling like, 'I want to make this moment indelibly imprinted on my mind because I'm not going to have this.' And her back was to my chest. And I have a vague recollection of a conversation. Lights out in the room, her lying on me and her saying, "So will you die with me?"

That was Liza. I think other kids might have just let it go.

"No," I said, "A part of me is going to die with you and a part of you is going to stay alive with me for always and forever."

Then she asked me if you can talk to people after they've died.

And I said, "No, not in the way we do now but kind of with our hearts." I told her that sometimes I think about Grandpa and imagine what he might say to something I've thought and that, in a way, that's a kind of talking and that I would do that with her as well. And that seemed to comfort her a great deal. So there was a continuing image of me living on past her to do that.

It was relatively easy to say these things to her because Lizie was so fueling and centering. She was a very easy kid to help. She was just so receptive and so somehow she made your own heart more available to you because she was so present.

There was another time when we were in the hospital. She was not yet terminal at all. We were post bone marrow transplant, she was having all sorts of problems but we were still potentially going for a cure. And her nurse came in and was hanging an antibiotic bag and she said, "I wanna tell you something when Ann leaves."

So I said, "Okay."

And again it was just before bed, that's when everything comes up. And my father had died right before her bone marrow transplant in September. And this conversation took place the next March or April, so she had time to think about it. And when my father died there were a lot of obituaries in the newspapers. She said, "Do you remember when Grandpa died there were all those notices in the paper?" And she said, "I don't want that when I die."

I said "Okay. How come?"

She said, "Well for people like" -- and she mentioned a couple and their two kids who we're very close with -- "I want you to tell them yourself. And then I want them to be able to tell" -- and she mentioned the two kids. "Because," she said "I don't think anybody should hear about that except from their parents." She said, "Dying is private. You should tell the people who need to know and they should tell their children because it's too much for a child to hear when it's not from their parents." And I was just so blown away that she was thinking about these kids' feelings.

I remember these conversations in part because they were life-determining conversations but also because we kept a journal. We wrote down everything that happened from the beginning. It was a way that Phil and I communicated because we would sometimes not see each other for days since we alternated shifts staying in the hospital with Liza. We would write down medical information in the book. Lizie's book, with her tape recorder and her cows, always went to every hospitalization. She would go to sleep and I would write down what happened. I wrote partly because I guess I was aware, even from the beginning, that one day we might not have her to remember with, and partly because it's always been therapeutic for me to write. So writing it helped me process it.

The death scene that Liza wanted came up several times after she first described it. We had many conversations about dying between the time she was diagnosed as terminal and her death ten weeks later. I asked her what she thought happened after she died and she thought that she would be with her Grandpa and other children who had died of her disease, in particular. She thought there was a leukemia ward in heaven, I think.

And in those conversations she would say, "And I want you to make sure that I'm at home when I die." We had a gray couch at the time, and I even think she said, 'I want to be on the gray couch. And I want to be on your lap. I want to be on your lap.'

From the moment of terminal diagnosis to her death Lizie got more and more physically attached to me. We thought of it almost as crawling back into the womb. And she would spend the evening hours just sitting on my lap watching TV. She wanted me under and around her at all times. And she would take naps on me. And I remember carefully trying to slide out from under to go to the bathroom when she was sleeping.

And I was terrified that I wouldn't be there when she died or that she wouldn't be on my lap when she died. I remember thinking, "What if I'm in the bathroom?" And actually hospice was wonderful for that because they made it very clear to me that I would do what I could and that if she died not on my lap it was because that's when it had to happen. The

implication was that people do have some control over the actual moment of their death. And that if she did indeed die when I was not underneath her then that was a self-determined event. That notion was tremendously relieving to me.

About a week before she died Phil and I were on our way to our weekly meeting with our hospice counselor outside of the house. And she said to me, "Mommy don't go. I don't want you to go."

And she'd never really said that. She wasn't clingy. Even though she needed to be on me, she accepted that she would do that when I was there. She didn't try to inhibit me from doing other things. I asked her why and she said, "I just don't feel right."

I missed that appointment and I sat with her on my lap in what we later understood really was a dress rehearsal for her death. I don't know whether she was near it at that point. She did not talk. She just sat on my lap. And I think that was some near-death moment. She had to be on my lap. And then she kind of rallied a little bit.

To Get to Be Six

We had an oncologist who was not comfortable facing Liza's terminal condition with her and did not understand that Liza was a 'need to know' kind of person. Although we had told Liza that she was dying, he continued to speak to her as though she were not necessarily terminal. The mixed messages made her anxious. We scheduled a meeting with him so she could ask him questions. We listened as she narrowed her window of remaining life to a smaller and smaller future. "Will I get to be seven? Will I live to be six?" We didn't prompt these questions. They were totally from her.

And he looked like, "Oh my God. I can't believe I have to answer this," and then answered her. He told her that she would not live until her seventh birthday and that he hoped she would live until her sixth. He told her that we would know when the day was soon and that he would tell her when her time was near. That conversation was reassuring for Liza. She knew the truth. She knew that we knew it. And she needed to know that we could all know it together. After that talk Liza grew less anxious. When she asked the oncologist, "Will I live to my sixth birthday?" and he said "I hope so," that became her goal. To get to be six.

Liza called her sixth birthday her "happy sad birthday". When people wanted to sing "Happy Birthday," she sang "Happy sad birthday to me." We had a birthday party which she helped plan. We invited family and some of our friends and two friends of hers from school who ended up cancelling the morning of the party. I think their parents just freaked out. And one of the clown care unit doctors Dr. Bobo who Liza really liked came as the

entertainment.

Liza and I made two cakes. We always make the cakes and the kids always decorate them. We put a big cloth on this table and put sprinkles out, and icing pens, and stuff and they can go to town. And Lizie sat and got into one of her things. And this was a creation on her part. And she did this whole thing where she wrote each of our initials E for me, P for Phil, M for Molly, C for Cleveith her babysitter, O for her grandmother, and L for herself. And she organized us around her and put little nonpareils around each initial.

And there was an exit place for her in this arrangement. There was a story of her moving forward. The way she described it the L was able to travel out. There was some pathway where she's surrounded by us but able to go. I understood that she was talking about being surrounded by us but dying. I almost didn't want to eat the cake because it was a story about her. So she really worked on this cake the whole night before.

And then we had the party and she had maybe one bite of cake and was vomiting. She just couldn't enjoy it. And the clown was too much, she couldn't take the stimulation. And she didn't want everybody to leave but she couldn't do anything. And it was very painful. It was the let-down of the other kids not coming and the knowledge that clearly this was the last birthday. And she was wanting to celebrate but also sensed how bizarre it was to celebrate at that point. It was just a very painful day. And I remember after people left we felt mostly relieved -- she had made it to the birthday, she'd made it to the party.

She died twelve days after her sixth birthday. She had been determined to live through her sixth birthday and her oncologist has said to us that she did that by pure spit and vim. It was just pure determination because she really was just riddled with leukemia and had no white cells left. But she wanted to make it to her birthday. But after that there was a sharp decline. She'd made it to the point that she'd promised herself. And my understanding from hospice is that this is not uncommon, that people will pick a date and get themselves there and then begin to fail after that.

Three or four days after her birthday I was giving her a sponge bath. She couldn't have real baths cause of all the various tubing. And I loved giving her those baths because it was a very body-contact time and for all those months in the bone marrow transplant unit we weren't allowed to have contact. And she felt so delicious.

And she said to me, "Mommy I'm tired. I'm so so tired."

And I thought, "Okay, here's my moment; she's giving me an entree to tell her it's okay to let go."

And I knew that she needed that. And partly I thank hospice for helping us understand that. Because it was so painful for me to give her permission to go that I don't know if I could have said it if I didn't understand how important it was to her to do that.

And that's when I told her, "I know you have to die and I know you don't want to and I don't want you to. But when you are so so tired that's okay. I will be okay because, and only because, I will always have you in my heart." And I pointed to my chest.

She had a great sort of witty response.

She said "Mommy that's not your heart, that's your breast."

Here this kid is dying, and she's joking with me. I said, "Okay so it's a little over there, but it's somewhere in that vicinity."

And then she said, "What's going to happen when you die?" Meaning, if I held her in my heart and I died what would happen to her. And I said, "Then Molly will hold both of us and Molly, if she has children, they will hold all of us. And it goes on and on and on and on."

After that, she basically stopped fighting. And we think of that as the pivotal moment that she really needed to just know from us that she could let go and that we would be okay.

The Death She Wanted

Liza died on a Sunday morning at around ten o'clock in the morning. The previous Friday was Molly's ninth birthday. Saturday was Molly's birthday party and it was a bowling party. I thought that Lizie was dying but we had twenty-five kids coming to this party. So Phil and Molly went to the party and Lizie sat in my lap really just clutching me. And she didn't want to move, she didn't want the TV on, she didn't want books. She just sat. And I felt like she was trying to hold on until they came back from the party. And I also think that she didn't want to die on Molly's birthday party day. I think she didn't want to ruin Molly's birthday. That may seem impossible, but if you knew Lizie I think you would see that it's possible that she would be thoughtful about the impact it would have on Molly to die on her birthday party day.

They came home from the party. And the rest of that evening unfolded with Lizie retching which is really just an awful thing but is a common terminal sign. And she was very uncomfortable ... flushed ... having a difficult time breathing. And we called the pain

doctor who determined that she would come over as soon as she could. Clearly something was dramatically wrong and we knew that we weren't going to rush her to the hospital and that basically this was it. And Molly was very dejected, sort of understanding that this was happening, and not having had a single moment with me the whole day of her birthday or birthday party. And so Molly went up to bed at around ten o'clock. And Phil and I just figured "We're gonna wait this out as long as it takes."

Lizie, by the way, after she asked for her lullaby tape to be playing when she died, for the next ten weeks she refused to listen to it. That night she said, "I want my lullaby tape on." She said that before anybody said anything to her about the fact that she was actually dying. And we just put it in; we didn't announce that as significant. And then she wanted 'I Love Lucy' on which was one of her favorite shows. She was Lucy-like. She was really a ham. But she really couldn't tolerate the stimuli of the television. And that was when the pain doctor came, gave her a lot of morphine, tried to get her to stop retching and told us that she felt this was basically it -- a matter of who knows how long -- she could slip into a coma and actually go for a while or she would die imminently.

Phil went up to get Molly because we thought it might be imminent and he brought her back down and Lizie said to Molly, "Molly it's my time to die -- they tell me it's my time to die and I want you to know that I love you."

It was so clear and so powerful and so much a determined effort -- with the few words Lizie could get out she wanted to tell her sister this. It was really clear that she somehow knew that Molly needed this to carry forward with her. And I think she was really taking care of Molly.

Lizie was very controlling, lest you forget. And to Phil and Molly's heartbreak that night that she was dying, she would not let anybody else hold her. And I think she was just scared that if she went to somebody else she might not die on me -- maybe she didn't realize she could control it as much as she could. So the others huddled around the unity of Lizie and me, but were not able to hold her which they had such a hunger to do.

Lizie had called for our baby sitter who'd been with us since Molly was born. And she and Lizie had the same birthday and 'Liza' happened to also be the name of the babysitter's mother-figure. So they were sort of cosmically connected from the beginning. And Lizie called her in Brooklyn and said, "You must come. I'm dying." This was Saturday night and Cleveth our babysitter was at her own birthday party and she came in anyway.

So Lizie sort of orchestrated. She had Cleveth there, she had my mother-in-law there. And then she said to me, "There's something I want to tell you but I can't do it." And I remember

Phil and I saying to her, "Don't worry, we know it." Because I thought that she was trying to do for us what she had done for Molly. But she was spent, she just couldn't do it anymore. And I remember feeling at the moment that we absolutely didn't want her to feel like she had let us down and not left us with anything. But afterwards I hungered to know what she was going to say. I want to have what we want Molly to have -- those last final words.

Anyway, at one point I left to go to the bathroom and she let Phil hold her. And when I came back she asked me to pick her up and hold her. And I picked her up. She was sort of chest to chest with me. And I tell you it's the weirdest thing. I don't believe in an afterlife. But she looked at the upper corner of the living room and she seemed to sort of get calm and was breathing easier and then she said, "Now ready."

Phil and I said, "Did she really do that?"

Everyone who was in the room said, "Yes, she did." And then she went into a coma, and died about eight hours later.

She waited for me to come back from the bathroom and pick her up and then she said, "Now ready." So maybe she had a sense that she had everybody assembled, she'd done the good deed for Molly. And Molly's birthday party day was over. She knew it was already the next day already, she knew it was like two o'clock in the morning, when she became comatose.

So she went into a coma, although didn't die, with her head resting on my shoulders. But I felt that was close to being on my lap. And then, as she lay comatose, we passed her around. Phil held her and snuggled with her and Molly held her. We have pictures of Lizie comatose on Molly's lap. My mother-in-law held her and all the people who wanted contact held her. And then we took her upstairs to our bedroom. We knew that we needed to lie down. And we all wanted to be around her and the best way to all be around her was to go on our bed. And we also felt we did not know how long this was going to take. She could be in a coma for weeks. So we had to find some way to live with this. Molly, Phil and I carried her upstairs. And then we laid her on her back propped up on pillows with us under her and around her. Molly was at her feet when she actually died. She was in my arms with Phil's arm basically around her when she took her last breaths. Terminal breathing has a certain rhythm. It's hnn hhh, hnn hhh. I can still hear it so easily. It's very vivid in your head. We were listening and then her breaths grew further and further spaced apart.

Something that came up in the hospice meetings before she died was that obviously this

scene where she's on my lap and we're all together was a dream scene. We were just lucky it turned out that way. It could have been that she would have had grand mal seizures, she could have had a stroke, she could have gone into a coma, not on my lap, and never come out of it and live like that for two months. So that it happened the way it did, we were just very lucky. And I think the pain and palliative care doctor helped a lot by making sure that she was adequately medicated toward the end. I don't know if it stopped seizures but I just think she escorted Lizie medically through it. Lizie really did have the death she wanted. It was just such a blessing.

Remembering Liza

A year after Liza died, we held a memorial service in her honor. A family friend who had played the guitar at all of Liza's and Molly's birthday parties, performed a song from Liza's lullaby tape: Carole King's "What would I do if I didn't have you to wake up to each day." Then we invited our dearest friends over to all partake in this bizarre meal made up of Liza's favorite foods. Mike and Ikes, five-flavor life savers, chocolate mint hard candies, beefsteak tomatoes, pizza cut into quarter slices. It was really a riot.

On her birthdays we let go of a balloon, a helium balloon. Usually something Disney. At ten she might have been tired of Disney but at six she was still completely immersed in it. Also, the Starlight Foundation had asked her what she wanted and she wanted a trip to Disney World. But she was never well enough to go. She never got to do that trip. So we send up a Disney balloon. Molly and I always do it. Phil actually doesn't. It's not his thing. We go to a playground which Lizie loved. I have a cherished memory of Lizie in that park. She's terminally ill and she's riding her bicycle. She has the tubing coming out of her chest into a bag and I'm holding the bag running behind her so that the tubing doesn't fly out of her chest. And she's biking -- terminally ill. That park was a place we always went. And so we go to the park and let the balloons go from there. Molly and I always get one for each of us.

The first year Molly wanted to write something to Lizie on it. And she wanted me to also. She wrote a note telling Lizie that a new brother was coming, I was pregnant at that time, and that she knew how Lizie would have loved this little brother, and that she missed her a lot. And it was just really splendid. And I wrote that this was a day when I remembered her a lot and that I remembered her every day anyway. And we taped the notes to the ribbons attached to the balloons.

We let go of them and sent them up. And mine went off and Molly's got caught in a tree. I thought, "Oh no, I don't want this to be bad for her."

And the wind was blowing -- and she had folded her note over -- and the wind just sort of

blew it open. I said, "It's being read. It doesn't matter that it got caught -- look we can see that the card's been opened." And Molly was relieved.

We've done that every year on her birthday. And initially we did it on her half birthday. But now we've stopped doing that. Her half-birthdays became very important when she was ill. We celebrated half birthdays which we had never done before. Partly in recognition on some level that we did not know what the next birthday would bring. But also because on her fourth birthday she was so ill, not yet diagnosed. On her fifth birthday she had just relapsed.

So no birthday was untainted and half birthdays became important.

This year, the fourth year of Lizie's birthday and death date, which are twelve days apart, Molly didn't want to do it. And I still felt I wanted to do it. And Phil and our son Sol came with me. And I got him a balloon.

And I was amazed, because kids don't let go of balloons easily. And if he gets one he holds on very tightly and if it bursts he gets real upset. But I told him in advance that this was a balloon we were going to have to let go, so if he didn't want to get one that was okay, but if he got it he had to let it go. It was a gift for his sister Liza. And to my amazement he embraced the experience and let it go. "Bye-bye balloon. Happy Birthday Liza. Happy Birthday Liza." And that moved me. I had a sense of carrying her forward with him.

3. Making Art with the Dying: A Hospice Worker's Perspective by Katherine Blossom

At the Connecticut Hospice, we work with patients grieving their own imminent death. A lot of our interactions really involve creativity and life review. The whole basis of our program is that creativity is itself a kind of life review, giving people a chance to not only turn inward and look at themselves but to turn outward and look at the whole world and review and explore.

The artistic process helps people come to grips with the fact that they're dying by allowing them to feel that there's some kind of eternal intangible framework around them. So making things and writing things and looking at or enjoying things that other people have made or written or performed gives people a kind of hope. Not hope that they're going to beat their illness and live but hope that it won't be for nought and it won't be lonely and it won't be bad as they thought.

Creativity is a form of control. When you create something you choose how it's going to be. And patients who are terminally ill don't have much control over any element of their lives and their family members often don't either. Patients often can't control their bodily functions or what they're allowed to eat or the fact they can't move, they can't control the progression of the illness, but they can control the things they make themselves. They gain not only a certain kind

of autonomy in that but pride. And it's something they can rejoice about -- a good thing, a positive thing in their lives that can be otherwise very limited and defined.

Family members can see their loved ones creating and also gain great hope from it and rejoice. And then they have often a tangible memento -- something that the patient made or did whether it's a painting or a sculpture or a card or a craft object or a tape recording of the story of their lives or a memory album of their life. The objects themselves are instilled with such meaning and history just like every human being is. It's something left behind for the family. Families always take home the stuff the patients have done. I've never seen it get left behind or thrown out. I know this sounds a little bit fluffy feel-good but it's very true.

For instance, one of our patients, Patricia Jones, was a young mother who had a teenage daughter Amy, and they had been estranged from each other for several years and really hadn't got along. Something had happened in Amy's childhood and we were never told what. But Patricia held within her this incredible grief. She said, "I feel really guilty about what I did to my daughter, what's happened to her." But she didn't ever tell us. Even though we gently tried to go there she didn't want to tell us. But that was fine. What she did want to do was have Amy's forgiveness or at least get in contact again. So she'd called several times but Amy hadn't returned her calls even knowing that her mother was here and dying. It was very hard for both of them. There was obviously a lot of unresolved pain.

Here in the art department we had the idea of making a memory album. We said to her, "What if you were to make a gift for your daughter, an album that could somehow say what you want to say to her that you can't say to her now on the phone because she won't call your back? What if your sister were to bring in small photographs and things?" Patricia's sister who was close in age and knew the daughter offered to help.

So we took about three weeks in the making of this album and she really did a whole life review. She started from her childhood. She said in effect "This is who I am. I'm human. I failed you, I know but I love you and I want you to know that I feel sorry that you've had some hard things happen to you and I didn't mean them to happen." She said a lot of this but she said it pictorially and with poems and quotations. And then she died and it wasn't quite finished. So her sister came back which was very brave and hard to do. She came back here two or three days after her funeral and continued on it and she promised to give it to the daughter when she felt the time was right. And then she got back in touch with us about six months later and said she had given it to Amy and it had been incredibly powerful and moving and the daughter had sobbed and sobbed and accepted and was still really digesting all of it. She also said that it had been healing for her too to see that the bridge had been made.

Often at the hospice, our patients reminisce about travel -- places they've visited that they know they'll never see again and there's that feeling of wander lust. They are confined and they can't just travel anywhere they want. That's a recurring theme. They talk about travel. Sometimes we try to satisfy their wishes. We've taken people down to the beach if that was their favorite place. There was a man who had been an avid gardener so we took him to the garden center, and he

talked about his garden.

But many times, we have to find new creative ways to satisfy that wish, so if someone wishes to be at a place and we can't physically take them there then we have to find a way for them to imagine it in their heads, to render it or translate it, draw it or paint it or make a collage that incorporates all of their favorite places, or to relive it in a way or tell stories about it. There's a lot of storytelling that goes on.

Not everyone want to review their life. No, usually the people I've worked with who are forty or younger the main issue is fear of what is about to happen and fear of what is about to happen to their young children. They very rarely do a life review. It's not about what they've done or experienced or seen or achieved, it's about what they haven't had the chance to do. So there's a review of a mission rather than the actual past because there hasn't been that long a past, there hasn't been enough. So even what there has been doesn't seem worth mentioning because of the bitterness of being taken away so early.

The younger patients are the most prolific artistically because they have this desperation to do more because their time has been cut short. Those are generally the patients who are most involved in the arts program -- they just work furiously day after day even long after they're physically able they still try. And when confusion or dementia sets in they're still trying and in a confused kind of way. "I've got to bake these breads" or "I've got to finish this picture." There's a great deal of trying to get things done. There's desperation. It's very sad to watch. It's really hard to watch.

Often, too we've had patients who've said, "Don't tell my wife I'm dying cause she doesn't know." And then at the same time the wife is saying, "Don't tell my husband cause he doesn't know." The family thinks the patient will feel that they have given up hope on them if they admit they really are dying. And it's really often through arts and music that those discussions come into the fore --when music is playing in the background, for instance. And it can take one simple outside external catalyst, a song that's sung at the bedside can trigger a whole range of emotions and long discussions, leavetakings and acceptances.

There's something very powerful about the end of a person's life that makes relationships very intense. There's incredible honesty. When you know you're going to die you haven't got anything to lose. You've got nothing to lose except your life -- and you know you're going to lose that -- and that's coupled with the effects of some pain killing drugs that reduce social inhibitions. It makes my job very rewarding. It's actually kind of an honor to see our patients let a complete stranger into their intimacies in the last two or three weeks of their lives.

I only wish people came here with more time so they could engage in these processes to a deeper degree. When you do a life review, when you present it in an artistic way, whether you write it, or you draw it, or you make an album of it, or sing it, you're stating who you are and you're making your mark. But it serves also the purpose of being able to let go. Cause you don't do that until you've come to the point where you know it's time to do that. How many people sit

down to write autobiographies unless they've accomplished something really major? For most people the major thing they're going to do is die -- so that's when they do their autobiography. And when it's done, if it get's done -- and it doesn't always -- it's a wonderful statement. But it's the starting of it, the act of thinking that way that releases a person in a way. To be honest it rarely is finished. It's often finished by a family member. But that, too, is cathartic for them. They're doing the same thing, reviewing that person's life and feeling the mixed emotions that they feel.

For our patients, the work is both humble and proud at the same time. It's the humility of letting go of this life, just letting things happen as they will naturally. It's also the pride of saying, "Here I am, here's what I did."

4. Creating a Home Altar

When individuals choose to adopt traditions from outside their culture and make it their own, they transform a communal rite onto a personal one. The creation of home altars is an example of this. Altars are places where contact can be made between between worlds. They are places where relationships with the divine or with the dead can be maintained through ritual activity. In some Catholic and Buddhist traditions, family members create home altars to honor and interact with their ancestors. On the Mexican Day of the Dead (*Dia Des Muertos SP?*), for example, when the spirits of the dead are believed to return annually to visit their families, the spirits are welcomed with earthly pleasures, like food, drink and cigarettes, set out for them on an altar or *ofrenda* . People who were raised in religions which do not include the tradition of home altars have adapted it as a means of ongoing commemoration of and communication with their dead. Marlene Lortev Terwilliger conceives of altars as sacred places that allow her to 'ritualize feeling'. Her sister's death from lung cancer at the age of fifty-two inspired her to make a commemorative altar full of personal symbolism:

"I knew that I could not return to 'normal' existence without finding a formal or ritual way of maintaining her presence in my life. I thought about a fantasy we'd shared...when we were old we'd live together in a little house by the sea. We'd need a library or a bookstore in town, and a cafe. The rest would be up to us.

"The altar took shape slowly. I knew the foundation would be a bed of sand... I discovered a marvelous deck of Alice and Wonderland cards and out of them constructed our house. It was perfect; a story from our childhood, and a link to our father who'd been great at amusing us with his talent for building elaborate structures with cards.

"Once the house was built I decided we'd occupy it in the form of Matisse women, odalisques who have always touched me and felt 'true' to us. I found a cafe table and chairs, coffee pot and cups... The next big challenge was the candles and flowers. I wanted a four candle holder for the four seasons, but none that I saw was right. Finally I found the perfect one, with mermaids, (who'd swim in our sea). It was only for three candles but that turned out fine because I found a separate holder that would be right for the candle of each season. Thus the changing of the

candles, a different color for each season, became an important ritual element...I had a Lucite box made, filled it with sand from the beach. I gathered pine cones, shells, stones at the beach, bought little objects I thought we'd have or would be there -- a typewriter, writing pad and pencil, a fish, a bird. Flowers were hard to come by. But finally I found some simple wooden Balinese ones and I knew they were right. I called the altar 'We Share The Moon,' a translation of the Chinese characters on the card in the center of the altar. On the backside of the card there is a poem--'I look up at the moon/And my heart feels you/ Although a thousand miles away/ Watching this same moon.'

The altar is very 'alive' for me. It continues to evolve and change as I add new objects: things Barbara might have wanted to include in our world, such as a pail and shovel for kids who might be at the beach, or our own grandchildren when they visited. Recently I added a little altar within the altar, and a skeletal bone I found on the beach.

In addition to letting the altar change as I find new objects for it, I also spend time 'keeping it up.' Readjusting the house, clearing sand from the steps, brushing off the typewriter. I love doing these domestic chores about the altar, but mainly I love and need the rituals. Each solstice and on my sister's birthday I perform a ritual. I buy fresh seasonal flowers, surround the altar with her pictures, change and light the candles, burn incense. I play music softly, meditate, speak to her, dance or cry... The altar is a memorial, a way of honoring my sister, of keeping her with me in my life forever. It is a way to express my grief and my love."

5. A Still Born Funeral told by Susan Knightly

Leonard and I had been trying to have a baby for years. Josh was just three weeks from his due date when we lost him. You know, the minute you feel a child kicking inside, you give it a personality. When the baby heard certain music he responded, and when my husband Leonard came into the room, he would respond with a kick.

The day of my miscarriage, I was home by myself. Suddenly, I sneezed and I felt a sharp pain and this bubble moving inside me. I got extremely flustered, and called 911. I don't remember what I said on the phone, but this wonderful police woman, who figured out the situation, tried to calm me down. She started singing Amazing Grace to me, and she was singing on the phone and praying, trying to sustain me till the ambulance arrived.

Josh was still alive when we reached the hospital. When he was born, I was awake enough to see that he was moving, then I blacked out. A few minutes later, the nurse came in and she had washed him and wrapped him and when I opened my eyes, I saw he looked just like my husband. He had his eyes, and his feet and his nose. It was so touching. Then the doctor came in, and I realized that the baby hadn't made it.

"What do we do now?" I asked.

"We send him to Staten Island," the doctor said.

"What is that, a dump?" I asked. "When babies are born who haven't breathed on their own, that's where we usually send them."

As I lay there and looked at my husband both of us were weeping. What made it even sadder is that I could hear the sounds of healthy, crying babies on the ward. Suddenly, we both knew that we had to do something for this child. I have always found that ritual helps any passage in my life, ritual has always sustained me, and this was a time when I desperately needed it.

Someone put us in touch with the Parkside Memorial Home, and they told us that they would arrange for the burial of the unborn child without charge. They were so nice. The nurse brought the baby the next day, and we washed the body. My husband wrapped Josh in his own Bar Mitzvah tallis (prayer shawl). He felt that he wanted to do that. The doctor was horrified.

We had a full fledged funeral for our child. We read poems, and friends brought their instruments, and we placed the poems in the casket with him. We even took a small sculpture from our back yard and put it over his grave in Cypress Hills cemetery, and we created a real feeling of life and death, of completion.

Even though the Jewish religion doesn't call for it, we sat shiva (the seven day Jewish mourning period). And I got to cry with witnesses, and I felt safer than I'd ever felt in my life. I have these wonderful women friends who attended, and I sensed they would hold me if I fell. Each of them shared stories with me about birth and about loss. All these women had suffered substantial losses. The whole invented ceremony had enormous meaning for me. I truly believe that ritual and stories are a way people can heal themselves around these issues where loss is overwhelming.

6. The Added Meaning of Coincidence After Death adapted from Marilyn Webb's *The Good Death*

A few months before she died at the age of thirty six, Judith Obodov Hardin made a pact with her husband Moh. Over the past three years she had fought breast cancer with all the chemotherapy and radiation that Western medicine could muster, along with natural healing, even a Native American shaman in Colorado. Each variety of medical treatment left not only physical but psychological scars. Western medical interventions assume that every person is their own doctor, and is able, for instance, to detect problems on their own body early; so Judith, suffering from cancer, had to cope with the guilt for not having visited a doctor sooner. Alternative medicine, on the other hand, often required total belief in non-traditional healing techniques, and when they failed, the onus was once again on her for not believing sufficiently.

In her last months, when a young Native American friend mentioned to her that if the shamanistic healing rituals had failed, the reason might have been that she didn't believe in

them, she answered bluntly. "Alex, I'm at a place in my life where I am facing my death. I didn't choose to be here. I am not here because I gave up. This is not bad. I do not feel bad about myself; it just is what is. When I die, it is not a defeat. Believe me. I have tried everything, and right now I am facing my death.

"Someday, you'll be here. I don't care how many spirits you have out there, and how many ceremonies you do, and how much you pray, you are going to die. Sam is going to die; all of your medicine men have died or are going to die. The Indian way has helped me very much, but a real warrior sees that death is not giving up. A real warrior knows that someday we are all going to die."

Judith's final months, chronicled beautifully by Marilyn Webb in her book, *The Good Death*, were filled with intimacy. Judith read novels aloud with her husband and children. At night, she and Moh would read Buddhist philosophy, and talk about dying in tones that were alternately serious and playful. As Webb writes, "They made a pact. Judith joked that if she could -- after she left her body-- she'd make the pictures hang crooked on the walls of her bedroom. Connie, the most meticulous of housekeepers was sure to notice! She also agreed to let them know as much as she could what it was like to die as she was in the process of actually dying."

As her family surrounded her bedside in her final hours, Moh noticed that she pointed to her mouth. He rushed to offer her a sip of tea, then a sip of water. Then he realized that she was telling him that she could no longer talk. A few minutes later she pointed to her eyes. This time Moh asked if she needed her glasses. Then he realized that she was telling him that she could no longer see. She was living up to her part of the bargain. When she died, Moh said his strongest reaction was that there was no more "Judithness."

Then, on the day before the funeral, Connie asked Moh if he noticed the pictures. "The pictures on the wall over Judith's bed. They are crooked." Some of them hung at more than a 45 degree angle.

"The time around Judith's death felt very magical," Moh later recalled. "It didn't take away the loss, the grieving. When she died I felt like a wide open slit had been cut through my heart. But these things, these funny coincidences, were there."

However much we acknowledge the secular world and its modalities of cause and effect, we often feel that the supernatural world speaks to us through coincidences -- like the pictures hanging crooked on the wall.

7. Daughters Craft a Coffin for their Father told by Peggy King-Jorde

My father always had a problem with coffins. He always used to say to my mother, "I want to be cremated." My mother was totally not going for that. He had a notion of his ashes being scattered in his garden so that he would always be there. He had this image of just sort of living on in the garden. My father, had a client who was an undertaker, who told him that many times

the ashes the family receives are really not the right ashes. So he thought, "Well, I'm not going to do that."

He had a very dear friend who was a minister who lived in Southwest Georgia. And when he died, this man was buried in a simple pine coffin on a hill under a tree. And my father absolutely loved that as an image and as a treatment of death. And so he used to say to all of us, my four brothers and me, "I want you to build me a coffin." But death, at the time, was so far away for us. So we didn't think anything of it.

When my father died, we were standing around his bed in the hospital. It was in Tijuana, Mexico because he had cancer and he was there for alternative treatment. So we were all standing around holding hands in the hospital. And, at that moment, we were actually happy that he was dead because he was in so much pain before then. He looked so restful. But then somebody said,

"What's next?"

And one of my brothers said, "Well, Dad always said he wanted us, his children, to build his coffin."

And so my mother looked at one of my brothers and me, because my brother Leland had also gone to school in architecture. And she said, "Okay, you two design and build Dad's coffin."

And so after the body was flown back to Albany, Georgia, which was our home, my brother and I sat in our family room and we drew sketches of the coffin on the back of an envelope for the shape, and the wood, and how were going to do the handles -- we wanted sisal rope handles. We designed it in a long rectangular shape, fairly deep and we put in tongue-in-groove planks which interlocked with one another and a flat top.

The funeral home that we were using was actually a new place. It wasn't this other traditional funeral home that everybody always used to go to. And the woman who was the funeral director was very supportive. We said, "We're not interested in buying a coffin, we want to build." And she said "Fine. I'll make one of my carpenters available. He has a truck, and he'll help you." And the next morning we got up; we met with the carpenter; he took us into a supply place; we collected everything that we needed down to the hinges and nails or screws that we were going to use and the sisal rope.

Then another friend of the family who made drapes and worked with fabric showed us an off-white, linen cloth for us to line the coffin with. And we asked her to make just a small cushion to line the bottom and a small pillow.

We took the supplies to the funeral home which was just a block or two from the house where our father was born. The funeral home was in a big old Victorian house And it had a beautiful big back porch. It was on the corner and it faced one street but you could see the porch from the side. This is a neighborhood where people sit on their porches, like they do in the South. But

people would walk by on the sidewalk, and stop to talk and see what was happening. My father was very prominent and they expected him to be in a very expensive coffin. And word had it that his kids were making his coffin. And so people would come up on the back porch to see. It was a beautiful spring day. And everybody was sitting out on the banisters and there was lemonade. And on the sawhorses we had this coffin that we were crafting. And it was funny, people would come up on this porch and they wouldn't talk about the coffin. They'd simply sit, especially a lot of the elderly people, they'd sit on the edge and they'd ask how everybody was doing and they'd almost ignore the coffin. Because, I think in a way, they were kind of amazed that it was actually happening. And there was an elderly man who was walking along this street -- it was lined with pecan trees and the branches formed a canopy above -- and he stopped and looked back at us, and walked a little and stopped and looked back and eventually came over to the porch.

The whole experience of being out on the porch was like a performance, particularly with this elderly man who watched from afar and eventually decided to come up on the porch, and sit, and sort of join, and watch, and not really talk about what was going on. People want to come as close as they can to certain events. Onlookers transcend and sort of transport themselves into a certain situation.

We spent time sanding the coffin down and just making sure the grain was very pretty. And our friend came over with the fabric and he lined the inside of the coffin and put the cushion in. And we started at 6am and we were finished by that afternoon.

I have such a wonderful memory of crafting the coffin. Maybe because it was such a beautiful day. And what I remember was that it really was just so satisfying. I felt like I was creating this very safe environment for my father. I knew that he wasn't really in his shell anymore but there was just something very satisfying about creating this safe place. And then after we completed it, the family just enjoying knowing that, "Okay, now we're ready to sort of let go." When I was working on my father's coffin, I felt a sense of mission, of purpose. The whole process of crafting and designing it helped my brothers and me to transcend fears associated with death -- not death itself but the effects of death -- how it impacted our family. My father had a very prominent place in family and everybody tended to rely on him. When I was working on the coffin, my focus was not much further beyond what was there, at that time and place, dealing with my brothers and other family members. I didn't expect to have that sense of satisfaction crafting a coffin.

Some of my friends imagine that it would have been a morbid or sad experience, but it was really contrary to that. It wasn't morbid. It wasn't sad. It was just totally the opposite. It was so satisfying. I would highly recommend it to anyone.

And once my father was placed inside the coffin, we put a spray of green on top. We had designed the floral spray that goes on top of the coffin, which was really not floral at all. My father really loved his garden which was filled not so much with flowers but with various textures of green. He liked flowers but he was not big on flower gardens. He really liked gardens

that stayed green throughout the winter months. And he would talk about the varying shades of green and to him that was the real beauty of his garden. So we went to a florist and picked out varying shades of green and shapes of leaves and designed a spray in all these various shades to create a texture. And we placed one red rose, which was a symbol of love, in the center. A photo of the coffin appeared in the local newspaper and made quite a splash. Other funeral directors actually called our funeral director to find out where she got the coffin. And people were saying they wanted to be buried in the same kind of coffin that my father was buried in. They talked about how simple and yet how beautiful it was. People, I think, were moved by the fact that the family made the coffin, particularly that the children had made it. My aunt turned to me and said, "You guys have to do my coffin too." My aunt was saying this as tears were flowing down her face. "I want the same thing for me. You guys have to build a coffin for me." At the funeral people repeatedly said, "I want my children to do that" or "I would love for you guys to do that for me." I think what appealed to people was the love that was put into it, and the sincerity that was put into it.

Somehow crafting this special place, this special vessel -- this was beautiful to a lot of people. I think it appealed to them in its simplicity. Many of them thought that because my father was so prominent he would be sent off in a golden coffin with tons of flowers. And the fact that the emphasis was not about that, that it was about something else, caught people off guard. But at the same time I think it caused people to get in touch with what this was all about; it conveyed the idea that this homemade coffin was 'a safe place'. The richness came not out of the purchasing of materials but out of the experience of crafting the coffin and taking care of our own.

My father wanted his coffin to be very simple and he didn't want a lot of money spent sending him off. Some people, like my father and me, hold these very morbid ideas about store-bought coffins lined with all kinds of stuff and fluff. It's gaudy. He had all kinds of design issues with that. And then the whole notion of a metal coffin was even more morbid. It was like, "What do you expect to preserve? Do you expect to go and open this coffin up later on down the line? Why would you have a metal coffin?" And he liked the notion that in a simple pine coffin that would deteriorate, he was going back to the earth -- the notion that death is a part of life, and that it's part of this larger circle.

Part of the ceremony at the graveside is that they lower the coffin a little just as kind of a gesture and then everybody leaves. And then the gravediggers get into doing the real burial. But as the coffin is being lowered, I'm sitting next to my brother Leland and we realize that the coffin lid, which is designed with just a little lip around the perimeter, is just a touch too big -- so that if they lowered the coffin too much it was going to start lifting off. We didn't necessarily want the coffin nailed or screwed shut. We just figured it's going to go into the ground and deteriorate and that's it. And they start lowering it and the lid is close to lifting off. And we're looking at it, my brother and I, and we're sitting there trying to give an eye to the guy who's operating this thing to tell him, "Okay you can't lower it anymore." So there was a level of comedy. And word has it from the funeral director that after everyone left they actually had to get a saw to trim off a quarter of an inch of the lid so that they could lower the coffin. We thought it was really funny.

We thought, "Okay...alright...some design flaws." My father would have thought it was funny.

But still, at the burial I felt an enormous level of pride because there were so many compliments. People kept coming up and saying, "My God the coffin is so gorgeous. And it was a very simple coffin. But I think that what people were seeing was the result of this collaboration among the children. A part of me went into the coffin. It's like any artist who feels there's part of them in something they've created. I felt that my brother Leland and I represented all my brothers in making the coffin. It's a part of all of us. It was something that we crafted and we created and so it was this sort of personal embrace that was going to be with my father's shell always. It gave us a sense of comfort for having created the vessel. I felt that there was a part of each of us put into the coffin. That's what made it good and that's what made it a safe place.

8. Making a Memorial Quilt by Sheryl Mullane-Corvi and Kathleen Doyle

In Victorian times mourning quilts were often pieced out of the clothing of the departed. The women who made them were helped, as they sewed, to literally, physically, work through their grief. The tradition has been revived by contemporary women including a Boston fabric artist named Kathleen Doyle who creates mourning quilts both for herself and for clients who commission her to help them commemorate their loved ones.

A Portrait of a Personality told by Sheryl Mullane-Corvi

Each block of the quilt has part of my father's shirt in it. And each color in the quilt represents a facet of my father's personality. The first block on the left is the purple -- because he could be quirky and silly. Like he'd be in the kitchen, and my mother would be cooking and trying to brush him away, and he'd just grab her and they'd polka. And then my mother would push him away and finish making supper. So he could be like that.

And the green was for his Irish ancestry. The browns were because he was a carpenter and a woodworker. And the blue was for the calm and steadfast family man -- which is what he was. And then you have some brown, blue, purple, and green, which he balanced really well, all around the borders. We talked about putting parts of his shirt in the borders too, but we decided that the shirt should concentrate in the four personality blocks.

And then I was envisioning red because he had this real drastic Irish temper. He could be happy and cheerful and then, at the drop of a hat -- you screw up and boy you wanted to run like hell. But you didn't see that very much. It was just really quick flashes of anger. So red wasn't supposed to be really dominant. It was Kathleen's idea to fix the red in the center of each block, so that it would be the home and the hearth, because he was really centered in the home. She told me that in traditional log cabin quilts, red representing the hearth, is in the center of each block.

My friend Kelly's mother met my father once. And I thought she described him really well as "a

generous man with a twinkle in his eye." And I was thinking of that when I was trying to incorporate things into the quilt. And I don't know how you would signify that, but I think it's there. My intention was that the quilt would be a portrait of his personality. And when I see it, I remember what he was like.

The Shirt

The shirt was what he was wearing the last time I saw him. I didn't set out to get it. I just took it because my mother's the type of person who doesn't like clutter. So on one of my trips up to visit her in New Hampshire after he died I remember thinking she was starting to throw things away and that I should take it. So I just grabbed it.

So I took the shirt which happened to be really typical of him anyway because it was plaid and it was beige and he always wore plaid. Unfortunately, his theory was that plaid goes with plaid, So he would wear plaid pants and a plaid shirt. Stripes go with stripes. Polka dots go with polka dots. And everything was brown.

So I had this shirt. It was just hanging around. For a while, it was on this big teddy bear I had, so I wouldn't lose it. But then I went through ten apartments in five years or something and it kept just getting stuffed into different places. It was on that damn bear for I don't know how long. He died in '91 and I just did it now, in '99 (?). So this shirt was traipsing around for eight years before I did anything with it. The teddy bear was stuffed in the closet. It wasn't a case of wanting to look at the shirt or anything. It was just a case of making sure I had it.

I can't quilt but I always intended that eventually I would figure out how to do it and I would make a quilt or something with the shirt. I didn't realize that this was done before. I thought I was being really original. I didn't realize there was any Victorian tradition or anything like that. All I knew was I had this wad of material being lugged around.

If I had done this eight years ago, one year after he died, what I wanted wouldn't have been the same thing. I think I wouldn't have had anything specific in mind. I think it would have just been, "Do whatever you want with this shirt" almost. Because everything was still chaotic and I hadn't worked through things or come to terms with things. So I think the chaos would have been just part of what the end product could have looked like, because I wouldn't have known what I wanted. And nine years passed and I was able to form these opinions of my father as a man so that the outcome is different now. Because nine years ago I don't think I knew him as well. He was still 'Dad' And now nine years later he's an individual.

Sacred Fabric and New Beginnings told by Kathleen Doyle

When I first received the shirt I asked myself, "What is this? Who am I to this?"

Some of the fabrics I use in my work are bought new, some I get in vintage stores, and some are my grandmother's old fabrics from her sewing basket or even her clothing. So there's this whole

collage of fabrics for me and then someone in Sheryl's position gives me a new fabric -- total curve ball, total foreigner coming into my world. I don't really have the emotional history with this new fabric; but in a way it's the most important fabric. I have this kind of sacred fabric to mix in with all my other fabrics. So the more I'm with this shirt -- I don't want to sound strange here, but -- the more it feels like a prayer.

And I feel like I have to live up to this. I have to live up to what she invested in it emotionally. So I feel entrusted with something, because when I first start cutting that shirt up -- like, this is the shirt that maybe her father had for decades and then she had for nine years. And then when I first make those first cuts in those fabrics, I have this big rotary cutter and I just hack this shirt. And in a way it's really violent. You can't put it back. And that's why I get a deposit and I have people sign and initial things because I'm like, "We have to be very clear that there's no turning back."

And I asked Sheryl if she wanted the little bits of the shirt that were left over -- the buttons and the collar stays. I saved them in a medical way in this little plastic bag, taking the threads off the button with tweezers. I just don't feel right, 'til the whole process is done, to do anything else with them. So I have my own little rituals of what to do with the scraps.

When I cut up clothing to make a quilt, the rending of fabric is permanent. This is the end of this and the beginning of something new. It's not a utilitarian thing anymore. It's not functional. It's not as it was intended. It's just accepting a whole new thing. And I really like to think this quilt brought something that in a way wasn't utilitarian -- that was on a teddy bear in a closet -- that was in a kind of grey period, in transition from being worn by her father -- to now. It has a new life. And it has a new identity. Now it's part of something new. I really like that idea of recycling and reinventing and continuing and incorporating change.

9. When Death is Disenfranchised: Private Rituals of Grief: The Beau Geste adapted from Erika Brady

Folklorist Erika Brady has studied private rituals of grief including those enacted by "those whose relationship with the deceased was socially ambiguous, giving them no clearly recognized social role in communal rituals surrounding death." She presents the story of Corinne D., a woman who had been involved with a married man separated from his wife. On a number of occasions he had threatened suicide but she had stopped taking these threats seriously. One night she received a frantic phone call in which he said that he was about to take an overdose of sleeping pills, something he had said many times before. After not hearing from him for two days, she visited his apartment where she found him dead.

"The pieces of a bone ring she had given him lay next to his hand, having split off his finger as the body swelled. After taking up the pieces she called the police. From that point, the funeral arrangements were in the hands of her lover's estranged wife, leaving Corinne with no defined role to play aside from that of the many mourners who were not members of the immediate

family. Privately, she begged the funeral director to place the pieces of the broken ring in the casket with her lover."

The placement of the ring in the casket clearly represented Corinne's affection for her lover. Brady proposes that it also can be interpreted "as a discreet challenge to those whose official relationship with him allowed them special rights over his body in death but excluded her." Furthermore, writes Brady, since the ring was shattered and had to be placed in the casket secretly, it also symbolized an unsanctioned and troubled love affair. . . . Sometimes, the community at large does not sanction the relationship of the mourner to the deceased; in these instances, grief and love must be expressed in secrecy.

Brady tells of a man who lost his gay lover to AIDS. The dead man's family, as next of kin, was in charge of the funeral arrangements but his lover managed to conceal a small lucky charm that he once had given his lover as gift in the hollowed out heel of one of the shoes in which he was buried. Such acts are almost subversive in their discreet challenge to family members who claim exclusive rights to the deceased. Sometimes, a personal rite is simply "an intimate act between the dead and living person not to be shared with others." Brady tells of a widow who after agreeing to remarry, tearfully dropped her first wedding ring into the ocean as a symbolic gesture, at that bittersweet moment in her life.

In one instance, recounted to Brady, "The sister of a man who died kept his tobacco pipes long after she had disposed of his other belongings. She couldn't figure out what to do with them. She finally made a little boat for them out of cardboard covered with aluminum foil and put them out to sea on his birthday."

Brady calls all such personal rituals of grief examples of the *beau geste*, selecting the name from a novel by Percival Christopher Wren. The French term *beau geste* means 'grand gesture.' The Beau Geste of the title represents both the hero's nickname and grand gestures carried out by Beau and later by his brother. When Beau dies as a soldier in the French Foreign Legion, his brother, remembering the "Viking funerals" they used to love to play at as children with tin soldiers and toy boats, gives his brother an improvised, symbolic Viking funeral.

The *beau geste*, is private rather than communal; it often is highly unconventional. It is often found in instances where conventional expressions of mourning seem unsatisfactory. Brady illuminates its power: "Expressing the importance of one person, one relationship, one life, each *beau geste* is a little essay on a particular loss, quietly defying the powers in life and death that level distinction."

10. Public Evidence of a Private Memory - One Hundred Smooth Stones for Grandfather told by Arlan Huang

Many people think I came to New York just for art, to go to art school. But the actual reason was to find out about my grandparents. They lived in old Chinatown. I was always very special to

them, although I was never quite sure why. As it turns out I'm the number one grandson of the number one child. So we had a close, long-distance relationship. When I moved here in 1969, attending Pratt Institute, I visited their apartment in Chinatown every weekend for dinner. The stories would abound -- while cooking, during dinner, after dinner. So I got to know my grandparents very well.

When I first moved to the city, my grandfather was still running his American grocery store in Little Italy. He came to America in 1911 at the age of fifteen. He came through Seattle and Vancouver. The first thing his relatives did was send him to work for the canneries in Alaska. The work was so hard that he ran away, and came back to Seattle. He worked in a couple of opium dens when he returned. Quite unusually, he was a Shriner, a Free Mason. A white man befriended him on the boat, coming to America. He told him about this organization, and said he would get him into it when he got to America. So he was a lifelong Shriner. A lot of Chinese at that time were sojourners -- they were going to make money and go back home. My grandfather was an entrepreneur. He wanted to make money and stay here. He even changed his name from Wong to Wong Jack Jones.

At one point he heard there was good opportunities in Bangor, Maine. So he worked his way out there and set up a restaurant in the Biltmore Hotel. It was a Chi-Am restaurant -- column A is Chinese food, column B is American food, hamburgers, roast beef, corn beef.

During that period he arranged to marry. It was an arranged marriage with my grandmother who was from a village close to his in Canton Province. For awhile they lived in Florida. But then my grandmother's family immigrated to New York, so the two of them moved back to the city. They raised six kids in that small apartment. We called her Ngin-ngin. Daddy called her Ma-ma. Grandfather called her Ngin. On her documents, Grandma is Chin-shi, "one of the Chins." Women didn't have their own names, so you would say "one of the Chins" or "Chin person." I spoke enough Chinese and my Grandmother spoke enough broken English to make life very enjoyable.

My grandmother died in 1976, and after she died things changed. Then it was exclusive. Me and my grandfather at the dinner table all the time. He would tell stories about everything -- how China formed, where the Wongs came from, how far the Wongs go back, growing up in China as a child, and all the relatives, as well as where the Japanese people came from, where the Koreans came from. Folklore, tales, myths, everything.

But one story that he told was actually very private. It was a life experience, a memory, and it was told about smooth stones, eels, and the river that ran through his village. It's a memory of his youth told in hindsight. It's a lesson. It remains the defining story of our relationship.

It was a private story and he would just tell me. It would come up every once in a while. And it was directly rooted in our ethnic past. It was about being within a particular group, within a particular village, a particular time. It gave me a historical perspective on the way he grew up in China and why he came to America.

After he died, that story gave me the idea for the project I called "One Hundred Smooth Stones for Grandfather." From blown glass I developed a method for sculpting smooth glass stones. I gave each stone a number etched onto the stone with a Chinese character. So each stone was numbered and coded to a story my grandfather told me, or a memory of our relationship.

I have a book that is completely private. It contains the stories, one to one hundred. I don't show it to anyone. The memories and the stories are private -- as I think a lot of memories should be. The idea behind the smooth stones is that there are these stories and these memories of a relationship and the stones are the evidence. That is the evidence that I want to give you. I don't want to give you the stories.

The culmination of the project was an installation at the Museum of Chinese in the Americas. It was an approximation of my grandfather's apartment in Chinatown, just a block or so away from where his real apartment had been. It was filled with objects from the apartment, an old telephone, a tin of butter cookies, worn dictionaries, chopsticks, a metal fan, and a wall calendar with a date establishing a moment in time. The centerpiece was the dining room table because that's where everything happened, the cooking, the watching TV, the mahjong games. In the installation, the one hundred stones are on the dining room table.

The evidence that I provide as an artist is that I have these memories, this relationship. The concept behind it is that every person has these memories -- however they store them, they're there and they're valuable, and they complete your life. It makes you connected.

I see each of these glass rocks as a touchstone, a genuine touchstone of that relationship, of that whole era. There are certain people who are links. My grandfather was the elder of his family in America. He was the link to his generation. So once he died, a whole generation was gone.

All people have an innate connection to river stones. It's the evidence of time and of time gone by because of its erosion, and because it's such an aesthetically beautiful object in any culture. So these stones are not symbols of mourning, but a celebration of life -- of life that has gone by -- but it's still a celebration.