essay

One Loss May Hide Another

BY CAROL LEVINE

t a railroad crossing at the edge of a Masai village in the heart of Kenya, the late poet Kenneth Koch saw a puzzling sign: "One train may hide another." It turned out to be a warning: Before you cross the tracks, make sure the first train did not block your view of another train coming straight at you.

The sign led Koch to ponder its deeper meaning. In his poem "One Train May Hide Another," he describes the many ways in which one event, one emotion, one experience, may hide another, even more profound meaning.

I thought of this poem recently after my mother died. This was a sad though not tragic event in my life. But in opening my heart to grief, I found that I was really mourning the loss of my husband's companionship, support, and love. I have lost my life partner, and not to death, which is final, but to a continuous series of reminders of what was and what might have been.

It is by any measure a terrible story, and the telling does not get easier with time. In January 1990, we were both in a terrible automobile accident on an icy road about one hundred miles north of New York City. My husband was driving; we were both wearing seatbelts. The car skidded, hit a guard rail, and flipped over and slid down an embankment.

Amazingly, I was unhurt. My husband suffered a severe traumatic brain injury. A testament to one of Amer-

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ican medicine's major successes, saving the lives of trauma patients, he survived, but with permanent severe disabilities. For the four long months he was in a coma, I read to him, played his favorite music, and showed him family pictures. When he gradually emerged from the coma, his thinking was chaotic. He had to relearn basic words and concepts. His moods alternated between rage and suicidal withdrawal.

In the anxious weeks he was in intensive care, I was still a wife. Doctors and nurses informed me of each day's progress or setback and treated me with kindness and concern. When he was no longer in immediate danger of dying, however, I became invisible, only to become visible again when I was expected to be the manager and hands-on provider of his total care. In retrospect I date my rite of passage to the first day of my husband's stay in a rehabilitation facility. A nurse stuck my husband's soiled sweat pants under my nose and said, "Take these away. Laundry is your job." Without knowing it, or understanding the consequences, I had become a family caregiver, a role I continue to play to the best of my ability while longing desperately to be just a wife.

My husband's rehabilitation and my anguish were worsened after a medical error caused the eventual amputation of his right forearm. When my husband came out of the coma, he repeatedly asked me to put his wheelchair in front of a mirror. He believed that his lost arm had been placed somewhere else on his body and that I was not showing him where it was. The psychologist at the rehab facility was kind, but the physical thera-

pists wrote off any possibility of his using a prosthesis or learning to use his left hand. My calls to the doctors who had promised me he would have a full recovery went unanswered. I was on my own, and I felt, and continue to feel, abandoned by the very system that saved his life.

Today, fourteen and a half years later, my husband is essentially quadriplegic, has significant cognitive deficits, and is totally dependent for all his basic needs. Eventually I brought him home from rehab to a new and more accessible apartment and began the daily regimen of managing his care and supervising the home care aides who were essential to move, bathe, dress, and feed him.

Providing him with the best quality of life possible under the circumstances requires an enormous managerial effort, the assistance of strong and patient home care aides, and a lot of money. While the medical side of the health care system sees me as a family caregiver, the financial side sees me as a wife and therefore the bill payer. As a spouse, I am legally responsible for the cost of his care; my only option for financial assistance was to "spend down" all our assets, become impoverished, and thereby become eligible for Medicaid. (This requirement does not apply to adult children.) I chose to keep

say as their last words. She used to tell me how her father, whom she adored, had taught her to say this prayer every night before she went to sleep.

The small Jewish cemetery, which I remembered from my father's death twelve years earlier as a bleak and wintry place, was lush and green in summer. Their graves are next to each other on a gentle rise, next to those of two of their closest friends. It seemed like the cemetery set from the last act of Thornton Wilder's play *Our Town*, where the dead residents of Grovers Corners speak of their past and welcome new arrivals. I could imagine the two couples, my parents and their friends, chatting through eternity about their children, their businesses, and the goings-on in town. At the end of the service, a bright yellow finch suddenly flew low over my mother's open grave and disappeared into the sky.

All in all, a "good" death, as deaths go. Certainly I felt a sense of loss and, after so many months of anxiety, the finality of her passing. The rabbi who conducted the service said to my sister and me, "Now you are orphans, and you must let people take care of you."

Perhaps it was those words, or perhaps it would have happened anyway, but in those first few days after the funeral I

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working, not just for the income, but as the only way I could see to retain my own identity.

Compared to my husband's constant and overwhelming needs, my mother's seemed manageable. She had reached her ninetieth birthday, and until a year earlier she had been in excellent health. Even after surgery for colon cancer, she had been able to maintain an amazing level of activity, outliving by many months the most optimistic prognosis. She lived in a small town in upstate New York, quite difficult to reach from New York City, where I live, and even harder to reach from Montana, where my sister lives. Even so, we kept in constant contact with her, visiting whenever we could and making sure that she had everything she needed. With a team of excellent home care aides and hospice services, she was able to stay at home, where she firmly wanted to be and where she could be in charge as she always had been.

The last few weeks were hard, as she lost strength and coherence. Alerted by the hospice nurse that the end was near, I flew to be with her. She died peacefully, as I held her hand and whispered the "Sh'ma," the prayer that Jews are supposed to

began to feel intense grief and anguish sweeping over me. Just as one train can hide another, one loss can hide another loss, and if you are not careful, you can get hurt. The hurts I had buried over my husband's condition were reopened, with a ferocity that surprised and even frightened me.

From the outside this fragile house of cards looks solid. I have, everyone assumes, reached some sort of "closure." I have "moved on with my life." After all, I work full-time, directing the United Hospital Fund's project on family caregiving, which is making a difference in public and professional awareness about the realities of taking care of an ill person in our complex health care system. My professional life, which started late because I stayed at home while my three children were young, is flourishing. I travel to give talks and attend meet-

But beneath my calm, in-control exterior is a void that can never be filled. There is no closure, if there ever can be for anyone in this situation. My husband's occasional flashes of wit and cogency, rarer with each passing year, stab me with sadness even as I laugh and compliment him.

When I told my husband that my mother was dying and that I would be going upstate to be with her, his only response, one I totally understood, was, "When will you be back?" His world has become so constrained that he cannot think beyond his immediate and urgent needs. I, who always looked to him to take charge, am now the captain, purchasing agent, navigator, and part-time crew for our plucky but overloaded little ship.

Had our dreadful accident not occurred, he would have, should have, been with me on this last journey to my mother's bedside. He would have comforted me, taken care of some of the arrangements, made sure I slept and ate, and maybe helped me laugh a little. My mother loved my husband; and he was always kind and gracious to her, even more accepting of her whims and idiosyncrasies than I was.

This renewed awareness of what for me is the real tragedy of my life became even more acute as my sister and I, and two of our daughters, began the difficult job of deciding what to do with my mother's belongings. As we went through drawers and closets, we kept uncovering mementos from my marriage. For several years my husband had worked for an airline, giving us an opportunity to travel that neither of us had had before. Wherever we went, we sent little gifts—a bunch of amethyst-colored glass grapes from Brazil, a porcelain figurine from Denmark, a coral necklace from Hawaii. My mother had carefully preserved each gift, either placed just so in its specially chosen position in her living room or neatly wrapped and marked in her dresser. And each gift reminded me acutely of that happier time when my marriage was a real partnership.

Even more painful were the postcards she had saved, most of them written by my husband. I had forgotten what a good writer he was, able to describe the essence of a place or an experience in the tiny space of a postcard. There were letters as well, telling my parents how much he loved me. One particularly poignant one, which I had never seen, was written to

my mother after my father's death. In it he told her how well she had managed this difficult time, how strong she was, and how much confidence he had that she would be able to find a new life for herself.

How I missed him! I had grown so inured to simply getting through each day, each crisis, each challenge, that I had let the part of me that still grieved lie dormant. And yet it took nothing at all—a postcard, a letter, a trivial object—to bring it all back.

Did I feel guilty about mourning my husband, who is after all still alive, when it was my mother who had died? Yes, a little, although I was comforted by knowing that I had done everything possible to make her last year full of love and caring. I was so grateful to her for keeping all the things we had sent her, especially since in the various moves I have had to make since the accident I have thrown out many other such reminders. I think she would have understood that grieving for my husband did not mean I cared less about her death. It only means that I had learned that one loss may hide another

Now, after her death, I have slipped back into my earlier mode of accepting the unacceptable. My mother's belongings are distributed among my sister and me, our children and grandchildren, and her friends. My husband's condition remains the same. I go on.

In rereading Koch's poem, I find that certain lines have new meaning:

When you come to something, stop to let it pass So you can see what else is there. At home, no matter where, Internal tracks pose dangers, too: one memory Certainly hides another, that being what memory is all about.¹

1. Kenneth Koch, "One Train May Hide Another," in *The Best of the Best: American Poetry, 1988-1997*, ed. Harold Bloom (New York: Scribner, 1998), 171-173. First appeared in *The New York Review of Books*, April 8, 1993.

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