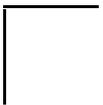
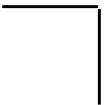
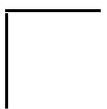
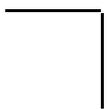


Part I

Personal Stories







John

1

1981. It was 2:30 A.M. when I woke up and found the empty space in our bed. John must have gone for a walk, and I wanted to be with him. There were intense, upsetting problems at the small Vermont school where he taught, and John had—for the most part—contained his anger at the situation, always hoping to be the peace-maker. As a result of that effort, he developed a serious stomach pain. He hated what the pain-relieving drugs did to him, and I knew he continued to be depressed. But just that night he'd taken me in his arms—as he so often did—and told me how much he loved me.

I threw on some clothes and tried following his footprints in the shallow March snow, quickly losing them. At the end of the driveway, something made me stop. There was the bright red truck that was his pride and joy. I struggled with the icy door, unprepared for the shock . . . his still, cold body was there, his deer rifle beside him! My husband, my love, was dead! His note: "I'm sorry, I can't stand the pain any more."

In hysterical tears I ran to the house, made phone calls to close friends and to the police. The next few hours were a chaotic blur of anguish while I struggled to hold on to some control of what was happening and would happen. I had to answer questions only I could answer and make decisions that I wasn't prepared for but were mine to make. My anger at the school, John's pain, and my loss exploded over and over in sobbing. But there was a fierce need to protect John, to care for him as I never would again.

It was an intimate life John and I had shared, intimate with each other and with the world around us. We were married at home, and John had wanted to be buried at home. But because the ground was still frozen, cremation seemed the only alternative. I would select the simplest procedure.

Opening the Yellow Pages, I reluctantly called a funeral home and inquired about the price of cremation. (There was almost nothing in the bank, and I wasn't even sure if I could cash John's next paycheck. I was panic-stricken about my finances.) The man told me cremation would be \$500 including the "required casket." But I didn't have that much money. I called the crematory in St. Johnsbury, 50 miles away. It was very early in the morning, but the telephone was answered by a Mr. Pearl. He did request a box but said it could be of the simplest construction, even

16

something I made myself. And the price of cremation? \$85 (1981). I thanked Mr. Pearl and hung up. Did I have the energy in my despair to build John's box? Probably not. My young children would be up soon and they would need me now. So I tried another funeral home.

"Well, the price for cremation, which includes everything, is \$700," said the funeral director.

Two more calls gave me costs above my bank balance, but when I pressed for itemized prices, I was given quotes as low as \$50 for the box or \$50 for transportation. Just in rough averages, I thought my expenses should have been well under \$250 for the kind of service I requested, without a viewing, calling hours, or other use of the funeral home. I couldn't understand it.

Because there would be an autopsy, the police called a funeral director to take John's body to Burlington. I plied him, too, with my questions.

"How much is the simplest box for cremation?"

"\$60."

"How much is transporting the body to St. Johnsbury?"

"\$50."

He saw me reaching a total of \$195 on a scrap of paper as I included the \$85 for cremation. I was thinking with relief that somehow I'd be able to manage that when he said, "But you'll have to add a \$325 service charge to that."

"What is the \$325 for?" I asked.

"Oh, there is a lot of paperwork," the funeral director replied.

I pointed out that the death certificate and the permit to cremate would be coming back from the autopsy with the body. That the only other document needed was a burial-transit permit.

"If it will save me \$325, I'll go get the permit to transport," I offered, not knowing that this fellow—as a deputy of the town—could sign them himself.

"I'm in business to make money," he said candidly.

Someone offered me money. "Let him do it. Let him do it."

But a quiet realization made me gently but firmly answer, "No," and the undertaker left the house.

Only months before, a friend in my writers' group had brought us her article, "How to Bury Your Own Dead in Vermont." Its historical background had awakened an identity with my own Vermont ancestors. The task of grappling with "arrangements" seemed enormous. I understood just how easy it would be to let a funeral director take over as I drained my body with tears. But I felt a strong need to express my love and caring for John, even in death.

I knew that under Vermont law I could transport the body myself. I would need the permit to do so, and it would mean asking for the help of a friend with a stationwagon or truck. But would I fall apart when I got near John's body? I needed to find out. I grabbed my coat and headed toward the door.

"Where are you going?" someone asked.

"I'll be back in a minute," I answered, not wanting to admit the purpose of my quest.

As I neared the group of officials at the end of the driveway, I could see the green body bag on the gurney, ready to be lifted into the hearse. And then I knew! Not only was I not going to fall apart, I was suddenly overwhelmed with the need to stay close. I knew that for me—and for John—my decision would be the right one.

Would this funeral director be willing to sell just his box? Yes. I asked if there would be a service charge to place the body in his \$60 box. There wouldn't. "Then call me when you get back from the autopsy," I said, "and I will pick John up."

That the total cost would now be under \$200 had become secondary. I needed to be a part of John's death as I was of his life. If I had had money, I would have lost that—given that away—in a moment of grief and confusion.

When our kids got up, I told them everything, as truthfully as I could. We all cried. The house was full now, and their grandmother took them off to play. (It was months later that their grief and questions finally spilled and continued to flow.) But I went on weeping, for our five-year-old daughter whose father would not be there on her wedding day, and our three-year-old son who would learn to fish without his dad. I moved through that day in a haze, a Tilt-a-Whirl of emotion. And I had calls to make.

I worried about asking my friend Richard to make the drive with me to St. Johnsbury. A sensitive older person who had lost his wife to cancer the year before, would he be uncomfortable on such a trip? It was not the way he had made his arrangements. But perhaps he'd understand. "Of course," he said, "John was my friend."

And so that snowy evening after the children had gone to bed, we drove to the funeral home to pick up John's body. The town clerk met us to sign the transit permit and share a hug. Then Richard and I left on the 50-mile trip, quietly crying, sometimes talking, sometimes silent. It seemed a long trip but one that should not be hurried.

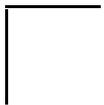
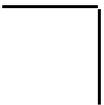
Mr. Pearl had agreed to meet us at the crematory even though it was well after usual business hours. As we unloaded the box, I knew I had to see John one more time, even if his body was now a lifeless one. Richard got a screwdriver from under the front seat of the truck. And as we lifted

the cover, I wept for the tender, gentle man I had married, whose life I had shared with so much joy. Then I softly patted his face a final good-bye. The person that I loved was living in my heart. I was ready to let the body go.



John had been a rare and special person, not just for me but for the many children he had taught and for those whose lives he had touched. I became aware that others needed to express their love for John, to share his death as well.

In the obituary, I asked the newspaper to announce an “Open House” in his memory two days later. It seemed as if hundreds came. We heard John's favorite music from “Oliver,” the show his Children's Theater Group had done so well the year before. And we were surrounded by flowers like the gardens he had loved. Our weeping and our laughing memories blended in a celebration of the gift his life had been to us.





Raphael

2

There was no notice in the paper, no formal obituary. But on this early summer evening, the dirt road was lined with cars and trucks. We walked somberly toward the rustic country home. I took a bucket with blooming iris and my shovel. With me were my children—one a next-year's kindergarten classmate of the boy now dead, the other slightly older—and Grandma on a cane.

Familiar people stood in quiet clusters around the yard, for the house was nearly full. I could hear a resonant voice though I did not recognize the reading and, as my children slipped inside, I followed to be near. They found other children sitting on a stairway and moved close beside the dead child's sister, looking down. Their eyes were on the body in the small pine box. Lupines pink and purple in casual arrangements were all around. But my attention sought the sorrow-laden parents—the mother with the youngest daughter in her arms, her husband by her side. I was glad the poem continued on, for I needed the comfort of that metered voice and time to weep my silent tears.

Then the parents shared with us the joy they'd known in this their only son, a child who had cared and understood their march for peace though he had stayed at home that day. Others offered, too, the happiness remembered—the boy who was so proud his father walked on stilts, the boy who had picked a friend that he would marry when he grew up.

A final reading drew us to the task at hand. An uncle closed the box, secured the lid. In quiet reverence, four assumed the burden of the load and passed on through the door. The children ventured next and led our way, a winding path through fern and woods. A tiny bell his father carried called us, too.

The box was resting by the hole, a careful oblong in the earth beside a birch, and on the boulder at one end a candle burned. His mother read the Song of Mourning in a Hebrew chant that others joined. Then one by one, we laid our flower bouquets upon his box, to share the journey on ahead.

It was his father who made the final move, who tearfully beckoned help to gently guide the box, with ready strings, to rest below. He took a shovel in his hands and stabbed the pile of dirt, then lifted it and cast the dirt into the hole. The shovel soon changed hands, and all of us—the children,

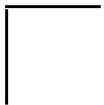
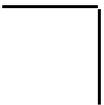
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too—moved earth to rest upon the flowers and the box. And father hugged a sobbing daughter as we filled the hole, planted iris and a rose.

It was a gentle singing that grew among the many there: songs of God, of Heaven, a lullaby. And though we choked and wept, we sang again—of love and life, in memory of this soul.



Raphael, age 5, died sleeping in his mother's arms. He'd had pneumonia, though no one—even doctors—had known. His parents brought his body back from the New York grandparents they had been visiting at the time of the 1982 June peace march. His was a country burial on their own land in Middlesex, Vermont. (First printed in the *Vanguard Press*, September 1982)





Mary Jane

by Steve Carlson

3

Although my mother was only 63 years old, her death was “expected,” at least by the people who worked at the hospital. She had been terminally ill for some time, and her doctors were amazed she held on and remained productive as long as she did.

Yet when the time came for funeral arrangements, we were not well prepared. We had to learn and plan quickly at a time of great stress.

Our failure to plan ahead was not, I suspect, unusual. Before she got sick, Ma was young and healthy, so there seemed to be little reason to discuss death.

Then, when she was stricken by a disease considered 100 percent fatal, she wasn't ready to die. As a teacher and writer, she had projects to complete and people who relied on her to help make meaning of their own lives. So she fought the disease.

Although she was given zero odds by the medical community, Ma was fighting to win. She said more than once she only wanted to be around people “who believe in miracles.” Could we doubt her? Did John Henry's family ask him what they should do if the steam drill won?

We weren't just humoring her. Friends and family alike became convinced that if anybody could beat back an incurable disease, Mary Jane could. Funeral planning was a taboo subject which, if it had been brought up, would have hastened her death and ended her hopes of achieving more of her life's goals.

Her foe was the AIDS virus, but the situation would have been the same if she had been stricken by cancer, stroke, heart disease, or any other illness more commonly afflicting people my mother's age.

She did hedge her bets in the final weeks. Weak and bedridden, she asked her four sons to be with her, in shifts, 24 hours a day. In addition to caring for her physical needs, she wanted at least one of us there whenever she was able to summon up the energy to talk. She had things to tell us and, by implication, there was little time left.

It was a difficult time for all of us. My brothers and I had to juggle busy schedules and important commitments, but being with our mother took priority at this time of need.

22



At her request, on June 16, 1986, Ma was rushed to the hospital in extreme discomfort. She told her doctor she was now able to prepare for death, since she was satisfied that the more important aspects of her life's work would be continued. She said she needed three days of medical care, with her sons at her side, before going home to die. She repeated, for emphasis, her desire to die at home, not at the hospital.

During the three days, she summoned us as often as she was able, straining to speak. She commented on our shortcomings, specific tasks she wanted us to accomplish, political insights, and Biblical interpretations. It was not feasible for us to bring up other issues for discussion. She had only a few words left, which she had to reserve for subjects of her choosing.

She mentioned funeral arrangements only once. She said she wanted a simple burial, not cremation, and specified a location that had spiritual significance for her. The energy she consumed by making the brief request completely exhausted her.

Consistent with the schedule she had set, on June 19th the doctors agreed to send her home. She died a few hours later.



Although none of us had experience with funeral arrangements, it didn't occur to us to delegate our final acts of love to outsiders.

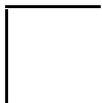
In retrospect, that may have been partly because of our experiences when she was bedridden. Ma had preferred that her sheets be changed by family members, for example, even though trained nurses were far more skilled at replacing sheets on an occupied bed. That was because we took the time to rub her feet. She remarked more than once she needed her feet rubbed more than she needed the sheets changed. Yet nurses always seemed too busy to provide that extra attention.

When it came time for burial and tribute, the qualities of thoughtfulness, consideration, and love seemed far more important than professional expertise. Those qualities were abundant among Ma's family and friends.

All official acts had to await completion of a death certificate by my mother's doctor, who was out of state and wouldn't arrive until morning. In the meantime, it was up to us to notify friends and relatives.

Sitting in my mother's apartment, I telephoned as many close friends and relatives as I could. But the telephone calls were emotionally difficult, and I didn't personally know all of the people who should be informed.

My mother did, however, have an address book and a home computer. I was not familiar with her word processing program and am not good at learning new computer languages. But somehow—I think with my mother's



help, but I won't try to convince you of that—about 140 letters were written that night.

My wife and I spent the night on the couch in Ma's apartment. Was it just a body in the other room or were we there to be with her? I'm not sure, but we needed to be there.

In the morning, after the death certificate was filled out, I called in an obituary to the local newspaper. The reporter was accustomed to talking with funeral directors who dictate the information in the newspaper's standard format. But she was patient with me as I struggled to recall the maiden name of my mother's mother, the dates of her various leadership positions, and the precise numbers of nieces and nephews.

There was a sense of urgency about burial once the permits were in order. None of us knew how quickly bodies decompose, so we didn't want to leave Ma in her bed any longer than necessary.

The family had been inclined toward cremation, but Ma had specifically requested burial, so two of my brothers built a simple pine casket and brought it to the apartment. Another brother spent an hour with Ma, quietly saying goodbye. Then each of us joined him, lifting a corner of the sheet to place Ma's body in the box.

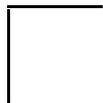
The burial site my mother had requested was unavailable, so we chose what we guessed would be an equally desirable location for her: a hilltop owned by her brother where she had spent many happy years.

We needed approval from the municipal clerks of the city where Ma died and the town where she was to be buried. Neither clerk was very familiar with the tasks, because the forms are usually filled out by funeral directors, who are deputized for that purpose.

Both clerks, however, were extremely responsive and helpful. After checking with health officers and other officials, they performed their duties with a minimum of delay.

My brothers and I transported the casket in my pickup truck and spent the next eight hours digging the grave by hand. It was hard work, in clay soil with many large rocks. We were eager to meet all legal requirements, so we dug the grave six feet deep. We learned later that the law required only five feet, which would have saved us about an hour of hard labor, but complaints were minimal.

This task culminated weeks of shared work and shared emotions that brought the four of us closer together than anything else we could have possibly done. For many years we had been separated by distance, careers, and individual commitments. By working together at a time of great need we renewed and strengthened our family bonds. For my brothers and me, the private burial was the best way to say good-bye to our mother.



But others also needed a chance to pay their respects. (Although Ma was deeply religious, she was not a church member, so we had no prescribed procedure for honoring her.) We took the easiest route we could think of. We announced a memorial gathering a week after burial, brought a few jugs of cider, accepted offers by others to provide additional refreshments, and played it by ear.

Scores of people showed up, including some who drove great distances. None of us knew everybody else. The only thing we had in common was that Mary Jane had touched each of our lives in profound ways. But that was actually a lot to have in common and, gathering together, at least this one time, was important.

Lacking any formal rituals, we sat around the hillside grave site, saying and doing whatever seemed appropriate. Some spoke words of tribute, some recalled meaningful incidents and experiences, some sang songs, some planted flowers.

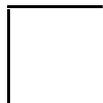
As far as I know, nobody felt uncomfortable, out of place, or unfulfilled. There were many comments about what a moving, special experience it was. Some of us remained long after the anticipated two or three hours, conversing and recalling our memories until sunset.

It would be inaccurate to say there were no funeral costs. Wood and nails for the coffin were worth a few dollars, as were the cider and other refreshments. People who drove to the burial site had to fuel up their cars, and I'm sure some of the flowers people brought had been purchased. But overall financial costs were so minimal that nobody kept track of who spent what. We were able to earmark whatever was left of Mary Jane's checking account (after her bills were paid) for publication of a book of her final writings.

We are not a wealthy family, but if any of us had thought that spending two or three thousand dollars for a professional funeral would have made the experience more meaningful for anybody involved, we would have raised the money. We have no regrets over our decision to handle arrangements ourselves.

We also handled probate ourselves, not a difficult task since there were few possessions and no disputes. The court clerk asked if the funeral director had been paid and was astonished to learn we hadn't hired one. No questions were asked about bills due to health care providers, utilities, or other creditors. Those bills got paid, of course, but we found it ironic that funeral expenses were the only obligation not entrusted to the good will and honesty of the family.

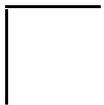
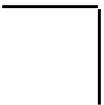
This experience with home burial is not offered as a blueprint for others. We were influenced by my mother's wishes, the needs of our family and friends, and the physical possibilities available to us. If Mary Jane's beliefs



26 ~ *Caring for the Dead*

had been different, or if there hadn't been a rural hilltop that was appropriate for burial, the arrangements would have been far different. Perhaps, in other circumstances, help from a funeral director would have been desirable or necessary.

But since death is a common human experience, there are a couple of general conclusions that may be of use to others. One is the importance of planning ahead if at all possible: in our case, hard decisions were made harder because they were delayed until action became necessary. Another is that personal involvement in death arrangements is a way of fulfilling emotional needs that probably cannot be met in any other way.





Hospice Didn't Know

by Jan Buhrman Osnoss

4

For the past two years, people have asked me “Why would you want to bury your mother yourself?” We hadn't set out to do it ourselves—it basically evolved as a process of elimination. We're conscious of our environment and try to preserve it any way we can. We do things ourselves whenever we can. When my mother was dying, it was natural that we began preparing for her death by doing some things ourselves.

My mother came to live with us after she was diagnosed with terminal colon cancer. We knew that she would die in our arms in the privacy of our home. My mother's life was a sorrowful one as she had suffered from mental illness for most of her adult life, so it was important that her death be dignified. Arranging for someone else to care for her was not a question—we knew that we would do most of it ourselves.

Choice. We choose how we will give birth, marry, and celebrate life's rituals, so I assumed I would have choices when it was time to bury my mother.

My mother was Catholic. When she was dying we were unable to find a Catholic priest in our area who was available to visit her. A Baptist minister, however, was available to come to visit my mother at our home. Discussion of the funeral arrangements began with him, and he put us in touch with the only funeral home in our area (we live on an island, Martha's Vineyard). We inquired about our options with the funeral home and were presented with a folder of services and prices, but none of the services met our expectations. The least expensive casket was made of particle board and was \$700. My husband, Rich, a woodworker and builder by profession, said he would build a nice box himself.

Years earlier, I remember my mother saying that she wanted to be buried in a pine box, and we thought we would try to carry out her wishes. When Rich arrived at a local lumber mill, he found that the owner had just milled some logs of cryptomeria that had been sitting unused for years. Cryptomeria is a wood which historically had been used in Asia in casket construction. It is cedar-like in its softness, light-weight in color, and exudes a rich aroma. The cost of the wood was under \$50. Rich was in the midst of constructing our home at the time, so he built the coffin during the course of his workday.

My sister, whom I see only every few years, arrived from California to be with my mother and help with the arrangements. As Rich was building the coffin, my sister and I began to discuss how the inside should be finished. We decided that it should be lined with blues and reds, as these were my mother's favorite colors. We went to the fabric store and picked out pillow stuffing, satin, a pretty blue and gold fabric, pillows, lace, several small silk roses (her favorite flowers), and red ribbon. We spent the entire afternoon and evening covering pillows and sewing the fabric together. As we sewed and glued, we shared—we talked, laughed and cried. The scent of the box filled the house. It was similar to cedar with an earthy sweet fragrance. It was beautiful. The preparations became the vehicle for us to grieve my mother's impending death.

Then came the actual logistics of pulling off a “do-it-yourself burial.” The first person we called was the cemetery caretaker. He thought our plans were feasible and informed us that we needed to purchase a plot, hire a grave-digger, and obtain a burial permit. I called the town clerk who said that I could probably get a burial permit through the Board of Health, but that they weren't meeting for some time. She also said that the funeral home acted as their agent for burial permits and hoped this wouldn't prevent us from doing our “own thing.”

The cost of the plot—which has space for three more caskets— was \$200. Our next step was to contact the local grave-digger and inform him of our plans. He said that we would have to purchase a concrete box called a grave-liner to be in accordance with the regulations of our town. His fees would be \$200 for the digging and \$400 for the liner. The price seemed high but not worth haggling about.

Hospice nurses came every day and were wonderfully supportive and encouraging of our plans in theory but voiced concern about the legality of burying my mother ourselves. A day or so after seeing the casket in our dining room, one nurse phoned saying that she had called the State Board of Funeral Directors. She said that what we were planning was completely illegal. She told us that we would have to contact the funeral home. I was reluctant to do this, as I knew the procedure and wanted to avoid the funeral home altogether. We had a casket, a grave digger, a minister, and a plot. I felt confident that we would not be arrested for our actions and could claim our rights through the U.S. Constitution's First and Fourteenth Amendments.

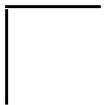
My mother died at 1:15 on Friday, October 15, 1993. My very dear friend Clarissa was with us. As soon as my mother passed away we began to wash her body and get her dressed. We talked about how we could get my mother to look her best, as my brother was due to arrive. Clarissa remembered visiting her family in Ireland, where they placed pennies on the eyelids to keep them shut. We wrapped mother's head in a scarf to close

her mouth. Our attempt at making her beautiful forced laughter through our tears.

The only thing that made the situation uncomfortable was the presence of an uneasy nurse who arrived at our house for the daily hospice visit at about the time my mother died. (This was the same woman who had called the Licensing Board earlier.) Hospice provided wonderful support for the dying but seemed to work against us when it came time to prepare for burial. It didn't make sense to me. I felt this was a very private and meaningful process we had chosen. When my husband carried my mother from the bedroom to the casket, a shoe fell off her foot, and my husband said to the nurse in humor that he was sure this would never happen in a funeral home. If we were breaking a law it wasn't to be malicious, destructive, or harmful. It was because we felt strongly that we could give my mother, even in death, the love that she deserved. At this point, the nurse said she was sorry but that she felt she had to step in. She said that we would have to include the funeral director because we needed a burial permit and the only way we could get one was from him. Relieved that she was gone, I didn't make much of her hurried departure.

We made the burial arrangements for the following morning: We called a bagpipe player, the minister, the gravedigger, and the cemetery caretaker. It was then that I understood the logistics of acquiring a burial permit. A death certificate comes from the doctor, and then a burial permit is issued. I thought I would be able to get the burial permit from the Board of Health after I had the death certificate in my hands. I called the doctor's office to get the death certificate and learned that the nurse who had left our house no more than a half hour earlier was already there at the doctor's office. I asked the receptionist if I could speak to the nurse. I told the nurse that I wanted the death certificate after it was signed. She told me that she had already met the funeral director at the office and had given it to him. She firmly told me that now it was in the hands of the funeral director, and I would have to deal with him! I had a hard time believing that all this signing and handling of papers had happened so quickly.

Feeling we needed to resolve the situation as soon as possible, my husband phoned the funeral director. The director said that we could do most of this ourselves but that we needed a hearse and someone to view the body. The cost would be \$1,900. My husband felt at this point we had no choice, and he agreed to the director's proposal. My response, however, was that I was not going to pay someone \$1,900 for something I was capable of doing myself. I called the director back and told him \$1,900 was too much money and that my mother would never have ridden in a hearse. He said that he "would look the other way" on the hearse but that someone from the funeral home must come to the house, view the body,



and witness the burial. He also told me that by law, the body (if it was not going to be embalmed) had to be buried within 24 hours of death. I could compromise but couldn't understand the rationale behind the now-lowered but still very high fee of \$1,000.

I was not comfortable with the funeral director's position yet didn't want to make any further decisions that would prevent us from burying my mother the following morning. Questions filled my head. My mother had no money of her own, and I wondered what would happen if I didn't have the money. Would she not be buried? Would she still have a funeral? Who would pay? I decided I would call the chairperson for the State Board of Embalmers and Funeral Directors (the same person the hospice nurse called). He told me that what I was doing was completely illegal and wanted to know where I was calling from so he could turn me in or turn in the funeral director involved. (Turn in to whom, I wondered?) He also said that the absolute lowest possible fee the funeral director could charge was \$1,900. I told him the reason I was calling was because I wanted to know what happened if someone was unable to come up with the money. He said he had *never* heard of a family who couldn't come up with \$1,900. He told me I could call the state welfare office and that they might provide support. The conversation clearly wasn't moving in my direction, and I didn't want to give him any more information so I hung up.

When I called back to tell the funeral director that we had decided upon a grave-side service at 10 A.M. the following morning, I was told that there would be no one available at that time to come to our home. When I asked about viewing the body and witnessing the burial, the funeral director's response was, "I'm sorry, Ms. Buhrman, no one from our office will be available at that time." I took this to mean that they were stepping out of the way and allowing us to go ahead with our plans without their involvement.

Before we put my mother in the truck on the morning of the burial, our son asked if he could see Grandma. My husband asked him if he wanted to see her head or feet and my son said her feet. Rich lifted up the end of the lid so my son could peek in. His response was, "Oh, wow!" My son was able to satisfy his needs and questions as they presented themselves. I felt truly connected to my mother and knew that our involvement in the entire process was very much a part of life.

The grave-side service was beautiful. The bagpipes played. My son placed five roses on his grandmother's coffin, representing one rose for each of her five grandchildren. There were several children at the service, and my three-year-old son was able to explain to other children his own understanding and meaning of dying and death. He was able to touch her and talk to her both when she was alive in our home and after she had died.

The experience and quality of involvement was something very personal. For me and my family, this was the loving and humane way to say good-bye.

A few days after we buried my mother, I received a call from the minister asking me to please call the funeral director, as he could lose his license for allowing us to bury my mother. I agreed to call, and the funeral director asked if I would come to his office and sign a release form and pay \$100 for the burial permit. I told him that I thought \$100 was a lot of money for typing up a few lines on a state-issued permit. He said that he had allowed us to do our own funeral but certain things, such as the price of the permit and signing of forms, were not negotiable.

I went to the funeral home on October 20, 1993. The director had a form ready for my signature with the date 10/15/93 next to where I was to sign. Then I began to read the agreement:

I hereby acknowledge that I have the legal right to arrange the final services for the deceased, and I authorize this funeral establishment to perform services, furnish goods, and incur outside charges specified on this Statement. . . .

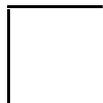
When I read this, I said to the director, “So here are my legal rights which no one seemed to be able to find when I wanted them, and *now* I am turning them over to you. This is exactly what I wanted from the beginning—my rights.”

The director restated what he had said before, that he could lose his license if I didn't sign the form and that it was a set procedure, that this statement came from the State Board of Funeral Embalmers and Directors. He asked if I wanted the funeral home to bill me the \$100. I said I would pay him then and there but that this would be the last money he would ever receive from my family for any future death.

I have since begun work with hospice to provide information on how a person can bury a loved one themselves if they so choose. The hospice folks with whom I have talked are now very supportive and eager for the legal details.

Being with my mother when she died and caring for her after her death made me acknowledge the celebration of life. It was a natural process for us. This may not be for everyone, but it should be made available to any family that wishes to be involved. Services, such as those offered by funeral homes, are there for those who need them, but those who wish to take burial arrangements into their own hands should have uncomplicated and dignified options as well.

When I am asked why I chose to bury my mother myself, I wonder why anyone would choose to have someone else care for a loved one's body.



32 ~ *Caring for the Dead*

We fear death, so therefore we let others handle it—only to rob ourselves of the experience that will help comfort our hearts. I believe, as Jessica Mitford and James Farrell do, that we must experience that which makes us human. I feel more connected to life because of this experience, and it has brought my family together as never before. All families should have this opportunity available to them.¹

¹ In April of 1996, after more than a year of legal research and lobbying efforts by Byron Blanchard of the Boston-based Memorial Society, state health officials announced that indeed local health boards could issue burial permits not only to undertakers but to anyone whose paperwork was in order. Although most have been cooperative, a few have been reluctant. The Memorial Society is prepared to mount a court challenge at any time a family is denied the requested permit.



A Conflict of Interest?

5

The hospice movement has improved the quality of life for the dying. Hospice programs have made it possible for families to care for the dying at home or in a family-oriented respite facility. But there are probably as many different philosophies for operating a hospice as there are hospices. In some, once the moment of death has arrived, the hospice person leaves. In fact, getting “too involved” with families leads to burn-out, the literature says. After-death arrangements are usually left for the family to work out with the funeral director.

It may even turn out to be the funeral director who serves on the hospice board of directors. One has to wonder if having a funeral director on the board might be a conflict of interest. At one hospice facility in Ohio, for example, the local memorial society was not permitted to leave its low-cost-funeral-planning information on a table—the funeral director on the board there objected.

Following is an e-mail that was received in the FAMSA office, edited for anonymity at the request of the writer who feared for his job:

I don't know. Maybe my perspective is different because I am a social worker, but I would have thought that the hospice movement would have embraced what you are doing. After all, our mutual concern is supposed to be for the patients and their families, right? As a social worker, I have been trained to advocate for the clients and to put their needs above any others.

I'll explain further. I used to work at a hospice on the East coast, and we routinely gave out cost surveys of the various area funeral homes to our patients without any problems from the funeral home industry or from administration. Then my wife and I moved here.

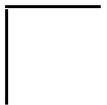
So, not thinking anything was different, I proceeded to call all of our area funeral homes to request the General Price Lists so I would have the information available for our clients. Sounded simple enough. One of the funeral homes, however, refused to send the info. Said if I wanted it, I had to come in to get it. And then he called my executive director to complain. I got called in by my director (not realizing I had done anything contrary to what I was supposed to be doing) and got told in no uncertain terms that I would refrain from trying to get any more GPLs. I was not

34 — *Caring for the Dead*

to provide the GPLs to anyone. The executive director then tried to take all the GPLs I had collected away from me. (I refused.)

Thanks for letting me vent. I love what I do, but some of these shenanigans bother me.

Perhaps the information in this book will stir more hospice programs that aren't already doing so to make available a wide range of resources on funeral planning. The following chapter demonstrates the value of knowing what the choices are.





The Most Awful Wonderful Thing

by Chris Sonnemann, R.N.
Oncology and Hospice nurse

Pediatric

6

When Yolanda died at age 14 after a 12-year battle with leukemia, her mother described the experience of personally taking her daughter's body to the mortuary—and then a few days later to the cemetery—as “the most awful wonderful thing” she had ever done. It is a sentiment I've heard from many others. It's one I've felt myself.

People who have spent weeks, months, or sometimes years caring for an ill person have done much for their loved one. Caring for them after death is a natural progression in completing the circle of care. In my experience as a pediatric oncology nurse—and most recently as a hospice nurse—I have noticed that families who care for their own dead have an easier time with their grief.

No, taking care of your own dead does not relieve grief altogether. People will continue to feel sad and lonely, and will experience the “fog” and lack of concentration that is part of the grief process. What they will not experience is the regret or “if onlys” that are common when there is no, or only partial, closure. It's important to touch and hold the dead body, and—for some—to wash and dress the body. I remind people that there is no hurry after death to have the body moved. It can remain at home for hours or days, whatever is comfortable. When people are given time, they become accustomed to the idea that the person is really dead, without the anxiety and wondering about whether the person is maybe still alive when the face is covered or the body is put into “the bag.” Often, as family and friends gather, the body becomes less and less the focus and people are able to reminisce and remember the loved one's life. Interestingly, there is often a lot of joking and laughter as tension is released and good times are remembered. It is a healing grief.



I personally experienced this for the first time 19 years ago when my father-in-law died while planting onions in our garden. Carl, who had been a country doctor for many years, had a history of hypertension and angina. It appeared that when he felt that he was having some sort of fatal episode, he leaned his garden tools against the house and laid down in the soil between the rows of vegetables.

We were told that because Carl had died unexpectedly we would have to wait until the coroner could speak to his doctor and release his body for

disposition. We were directed to a local mortuary that could pick up and keep Carl's body until the coroner signed the death certificate.

Once the body had been removed, we had a chance to explore what to do next. Carl's wife Ruth favored burial; my husband Tom and I suggested cremation. We also called his parents' minister for counsel and support. When the minister asked what Carl would have wanted, we realized we really didn't know. We decided to get some sleep and settle things the next day.

Rising in the morning, we found that Ruth had gotten up early. She said she'd felt compelled to find a journal Carl had been keeping when he occasionally couldn't sleep. In this journal she found instructions, written some months earlier, for what he wanted done with his body when he died. He wanted to be cremated and have his ashes scattered among the giant redwoods in a nearby state park or on farm land that they had owned in northern Michigan.

Once Ruth read Carl's journal, our direction was clear as we proceeded to carry out his wishes. We found a crematory and learned what we would need to do to have his body cremated. We were told that we would have to get a death certificate signed by the coroner or his physician. With this in hand, we could then proceed to get a Permit for Disposition which we would need for the crematorium. A container of some sort would be required for the cremation, but it could be as simple as a cardboard box which they could provide for \$15.

After much discussion, we decided that—rather than hiring the funeral home—we could do the necessary paperwork and transport the body ourselves. The funeral director was somewhat surprised by our decision but once he understood our determination—that we knew what had to be done, and that we had the right to do this—he became cooperative and helpful. We wrapped Carl's body in a white sheet, lifted his body onto a gurney, and finally loaded it into the back of our van. None of us was sure how we would feel about touching and handling his dead body. Wrestling with that uneasiness and doubt was far more difficult than the actual task proved to be.

As we drove to the coroner's office downtown, Ruth cautioned Tom to drive very carefully. If we got stopped for any infraction we might have an uncomfortable time explaining Carl's dead body. It was amazing how easily we found we could laugh at ourselves and at the situation we found ourselves in. The healing had already begun.

With the proper forms in hand and Carl's body wrapped in the back of the van, we headed for the crematorium. I went in first to pay the fees. The man at the desk told me that his family had owned the crematorium for 45 years and that it was becoming more common for bodies to be brought directly to them without a funeral service first, but this was the first time

in his memory that a body had been brought by the family. He helped us remove Carl's body from the van and place it in a box on the gurney. We then each took a few minutes to say our final goodbyes, shed a few tears, and left him there to be cremated the next day.

As we drove home we all expressed a surprised feeling of euphoria. We smiled, laughed, and talked of how pleased Carl would have been knowing that we had done all we could for him by ourselves and that it had cost less than \$200. We felt a closeness—defined by having cared for Carl in those last hours. Family members knew of Carl's negative feelings about the funeral industry and his desire to not be taken advantage of, but we knew that few could grasp the meaning of what the three of us experienced and felt.

We learned much from our experience. We learned the importance of writing down wishes—having written instructions was a gift left for us by Carl. We learned the power of knowing what was lawful—what we could and could not do. Being able to be clear and express to others what we did and did not want, we were not influenced—even in a state of shock—by “what is usually done.” And most importantly, we learned of the healing that came with doing all that we could for someone we loved.

Since that time, I have helped take my own father to be cremated. After her experience with Carl, Ruth asked that we arrange things in the same fashion for her. I have also assisted numerous times when patients were taken directly to the mortuary or crematory by family members. I let people know that they legally have this choice and encourage them to talk about it ahead of time.

I especially urge parents dealing with the death of a child to take some part in the funeral rituals. The need for constant care and attention when a child is ill is very intense. Death seems inconceivable. The emotional emptiness when the body of a child is abruptly taken away seems to deepen the despair, making it that much more unbearable. But the sense of “having done all I could” has profound healing effects. In my experience, no parent has ever regretted having done at least a portion of the funeral preparations.



One of the most profound experiences I have had as a nurse was with Morgan, a young oncology patient, and his family. I developed a special relationship with Morgan. It was not, however, love at first sight. Morgan was not happy about coming to the oncology clinic, and for about nine months he had used a protective cloak of silence to avoid interacting with the clinical staff. I learned long ago not to take such defenses personally, and I don't give up easily. So I kept talking with Morgan—telling him about my own three sons and asking Morgan about his life outside the clinic. One day,

Morgan arrived at the clinic carrying a “He-Man” figure. Having had personal experiences with these characters through my own children, I began a discussion that broke the ice between us forever.

When treatment failed and it became clear that Morgan would not survive, I visited his home more and more often according to his needs. That meant there would be no more interruptions of the continuous infusions of morphine that he was receiving to combat the intractable pain due to metastases of his bone, the result of advanced Neuroblastoma. I sometimes made the trip alone and sometimes with my family, on weekdays or on weekends. My boys played with Morgan and his sisters, and I used those opportunities to talk with Morgan's parents about what to expect as he neared the end of his life and to reassure them that they could help him in dying by just being with him.

As Morgan's disease progressed, he required increased transfusions. I borrowed an IV pole from the clinic, loaded the family ice chest with blood products, and cared for Morgan at home in his own bed.

During this time, Morgan's most comfortable position was propped against the front of his mom or dad. Because his parents alternated this “holding” continuously, it was clearly taking its toll on them. Shortly before he died, I was able to convince Morgan that I could take a shift at holding him so that his parents could take a much needed walk together. In the safety of those moments, Morgan talked with me about his fear of the unknown and sought my assurance that his family would be okay after his death. He wanted to know if dying would hurt and if his family would be sad. He asked if I thought that they would forget him. I told him that I believed that death would relieve him of his pain and that though his family would be very sad, they would never, ever forget him.

The day before Morgan died his parents asked me to talk with his sisters, ages 8 and 14, about his impending death. The parents were concerned that they lacked the strength and energy to make it clear that Morgan would not improve this time as he had always done in the past when he was ill. I took the girls out into the garden to tell them that Morgan was dying and what they could expect when he died. We always try very hard to make the siblings of our patients feel that they are an important part of what is happening. At first they snickered and didn't really believe me. Then, as the reality of what I said sank in, they became angry and ran to their rooms crying. I returned to help care for Morgan so that his parents could comfort his sisters. I still recall this as one of the most difficult things I have been asked to do as a pediatric oncology nurse.

I was called immediately when Morgan died and drove the 40 miles of winding roads to his home that night. After a time of embracing and quiet discussion about the details of what had happened when Morgan died,

I asked the family if they had thought about what their next steps would be. The topic of funeral arrangements had been broached before, but the family had never been able to accept making those arrangements.

I was able to share with them their legal choices for handling Morgan's body. I informed them that they could keep his body at home with them until they decided what to do. I reassured them that they needn't call a hearse immediately to come and take his body away but that they could transfer his body themselves when they were ready. Because they had decided that Morgan was to be cremated, I informed them that his body need not be prepared in any special way for disposition. The family seemed very relieved.

They kept Morgan with them at home for two days. During that time, they were able to adjust to his death and say their goodbyes in their own way and their own time. I returned each day to support and encourage what they had chosen to do. I arranged for the death certificate to be signed and the disposition papers to be completed so that Morgan's body could be cremated without complication.

Morgan's dad and uncle built a casket of pine wood. Friends from school, friends from the community, and relatives had time and opportunity to come by and paint a picture or write a message to Morgan on the casket that would be cremated with his body. What a wonderful final gift Morgan's family gave him, and to all those who loved him, by opening their hearts and home to others who needed to say goodbye and grieve. When the time came to take Morgan's body to the crematorium, his parents tenderly wrapped him in a sheet, placed him in his decorated casket, and drove him to the crematory themselves.

Morgan's parents have been a wonderful support for other families who are facing the death of a child. They are able to share how their grief was eased by having done all they could for their son, even in his death. Indeed, those parents who handle all funeral arrangements themselves seem to heal more quickly. The hands-on experience brings an inner peace in spite of their loss.

