

Clouds and the Crystal Bell

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*a daughter's remembrance of the extraordinary death of an ordinary woman
and a tribute to the staff of Angela Hospice (1998)*

The bell tinkled for the second time that night.

"I'm coming Mom."

She was sitting up again. The pain had returned.

"I'm starting with 20 this time," I said sitting down on the bed and stroking her back. I reached for the little bottle and the eyedropper on the table we had set up alongside her bed. This time her face didn't bunch up from the bitterness of the clear liquid that had to be held under the tongue for a minute before swallowing.

A week before, I had joked with her on another night like this. "I know why they make it so bitter! To keep you from wanting to use it so much you'd become addicted." Roxanol, a brand name for morphine, was one of many gifts from Angela Hospice. It was not something her doctor would have prescribed on his own. To start morphine is pretty much to admit defeat. Like so many good doctors of his generation, Mother's doctor was determined to succeed.

Just three days earlier my mother and I had a conference with him in his office. Our mission was two-fold: To obtain assurance that he would allow us to keep the Roxanol and to secure from him 'standing orders'. The term was strange to my ear, but Diane, our nurse, had made sure I understood what it meant, as this was the only way to give my mother the assurance she demanded. Standing orders meant that we would have a chance to do it on our own, without the hospital and yet without the pain.

We would have a chance to do death the way we wanted, if only death would oblige. I say "we" here rather than "she" because under a hospice program there is no such thing as a patient. There is a patient-and-caregiver. Caregiver was a rather unusual role to find myself in—having never had children in the usual sense (though I do count my books and my good deeds as children). Also, I was very much a Barlow. That meant I was not a gushy, warm person. Barlows are reserved, stoic — and darn proud of it.

"What I see here is a depressed woman," my mother's doctor of thirty years said as he took his seat for our conference. "What?!" I responded in disbelief. "Ever since my mother was first visited by hospice staff, it's been like a psychological cloud has lifted."

"Well a year and a half ago she was in here complaining of loneliness."

"Not surprising, at that time," I responded, "as she was beginning to truly miss the companionship of her husband."

Mother had been widowed twice, most recently three years earlier. Though the 27-year marriage had been difficult, a partner is still a partner. And there is loss.

Next the doctor launched into a soliloquy, explaining why he had pulled my mother off hospice just three weeks after his assistant (in his absence) had approved our request. I can't remember the details, as his arguments were utterly alien to my ears. But I do remember sharing a glance of disbelief with Mom, who was sitting alongside me throughout, when he described his abilities to triumph over congestive heart failure by telling us of a patient doing well on kidney dialysis three days a week.

My mother and I are dissimilar in many ways. By brute force, and thanks to the budding feminism of my generation, I had learned to overcome her/my passive approach to authority, to life. But she and I share a philosophy of death. Mine comes from reflection in the abstract, a commitment to a scientific view of life (and, hence, a belief that without death there would be no life), and the ideals of a still youthful 40s. Hers comes from experience. Her body had been failing bit by bit for years, and she had been spending more and more time each day simply taking her medications, filling syringes, attending to personal hygiene and salves and bandages to relieve discomfort. She was tired, but she was also fulfilled. Her life had been lived as well as she could have lived it. She had no demands for fresh experience; it was time to go. And she was contentedly spending each day working through her "to do" list—final tasks to ensure that everything would go smoothly for the family after her death.

One morning I decided to depart from our usual business of deciding which items on the list to attend to that day. I asked, "In the weeks or months you have left, what sorts of fun things would you like to do, so we don't spend all our time simply attending to death?" She paused in thought and then offered meekly, "Play more Scrabble and Rummikube in the evening?"

"I'll need to ask Deb for assistance on this," I thought to myself. Deb was the social worker hospice had assigned to Mom. She was in charge of my mother's psychological and social needs, which included the offer of spiritual guidance by clergy associated with hospice. In hindsight now, I understand the lack of interest in "fun" as simply being a natural passage, a sign of readiness for death. But at that time, I ascribed

it to extreme passivity—my mother having never really thought about what her own desires might be.

Mother was now 75, and she had lived almost her whole adult life in service to family, giving birth to her first child at age 29, to her last child at age 48. Then, a year after her last left home, he was back again with an infant daughter in his care—which meant her care.

Around this time, she had bypass surgery. Mother had been told she would never leave the hospital without it. Above all, she did not want to die in a hospital. It didn't take long, however, for her to be more than grudgingly grateful for that surgery. Without her full-time presence, her youngest granddaughter would not get the mothering she would need.

When Kendall was three my mother suffered a bout of severe esophageal bleeding that would have killed her had not her son arrived home in time to call 911. The hospital doctors diagnosed that blood vessels of the liver were blocked and thus responsible for back pressure in the hepatic vein—a not unreasonable conclusion, given Mother's heart trouble and diabetes. But she and I decided upon an alternative diagnosis: irritation of fragile diabetic tissues from a terrible, month-long bout of bronchitis. Nevertheless, fearing another episode and the extreme discomfort of vomiting blood, she turned to hospice as an alternative to 911—just in case.

Her life hadn't changed at all at that point. There had been no "decline." She was still bowling, still driving, still hiking up and down the basement stairs to do laundry. So when several weeks passed with no more bleeding episodes, she voluntarily signed off. Hospice didn't cost her a dime, as her Medicare was supplemented with an excellent Blue Cross policy, thanks to General Motors, the lifelong employer of her recently deceased husband. But as with family, so with society: Mother didn't want to be a burden, nor to take what she didn't absolutely require.

More, she simply wasn't ready to die quite yet. She had work to do. She vowed to see her little girl into first grade.

She almost succeeded. Grandma died six weeks short of her goal.

She would have died two months earlier, had Kendall not been able to call her Aunt Shirl in the middle of the night. That heart attack put Mom in the hospital for eight days. She was finally booted out of intensive care and into a wheelchair headed for the door after a cadre of doctors had failed to convince her to submit to invasive diagnostic procedures.

"I don't need to know how much I damaged my heart this time," she told me afterward. "I'm not going to let them do anything anyway. No more surgery. I just want to be home."

As it turned out, even if she had submitted to diagnostics, her doctor might not have changed his judgment. His willingness to approve Mom's request for hospice designation after the esophageal bleeding had, after all, proved premature.

"Doctor," I said. "Things have changed dramatically since my mother was in the hospital. It's just not the same."

She had given up driving, and she was exceedingly slow at just about everything now, though she laughed as quickly and as fully as she always had.

"Let us tell you about her episodes of pain," I suggested. I had brought with me a list of the dates she had experienced enough chest pain at night to require one or two or even three doses of Roxanol. And I had included in that list the exact location of her pain—sometimes by a rib, sometimes under a scapula, sometimes threatening to encircle her whole chest, as it had the night of her hospital emergency. I had also made note of whether the pains were accompanied by a sensation of wet breathing, which is a sign of fluid gathering in the lungs. Our hospice nurse had always been interested in this level of specificity, so I assumed he would be too.

As I began, the doctor broke in to give me an unwanted lesson in the anatomy of the heart. That wasn't what we were here for. I had an agenda. I knew he had limited time, and diversions didn't sit well with me. I tried again. At one point he mentioned "arthritis in the chest" as a possibility. This, from the man who had put her on nitroglycerin several years earlier and who had switched her to what she referred to as her "wonder drug" when the pills had become an everyday—many times a day—necessity.

"Doctor, do you think my mother is ever going to die?"

"We are all going to die," he matched my sarcasm.

My recollection of the conversation that followed is hazy. I remember most my anger. More than anger, I was incredulous. Somewhere along the way my mother boldly insisted that she, for the first time, be heard. Again, I don't remember what she said, but I do remember being proud of her.

Time was passing and tensions rising. I moved to our bottom-line requirements. "Doctor, in order for my mother to get the assurance she needs for a natural death the way she wants to die, we were told by our hospice nurse that we need to secure two things from you: We need you to agree to continue to authorize a prescription for Roxanol, and we need you to issue standing orders."

He agreed. The meeting ended. My mother and I walked out relieved. As it turned out, we never needed to fill another subscription of Roxanol. My mother was signed onto the "skilled care" program of Angela Hospice the very next day— and two days after that she died.

Under skilled care, the goal is to maintain life, not to provide a comfortable and fulfilling death. And so I knew that whenever the final dance with death would come—in whatever form it might take—Mom and I would be pretty much on our own. If I phoned skilled care for on-site assistance, I would have to be prepared for their recommendation upon arrival that Mom be moved to a hospital.

Nevertheless I could call upon the nursing staff for advice in the middle of the night. On the night of Mother's death I did that twice. The night nurse who took my first phone call calmly and competently led me through the procedures.

"I think she's having a heart attack," I began. "She says she has pain down both arms, and she took a nitro earlier this evening. She's burning up, and wants cold cloths on her forehead and neck, but when I took her temperature it read just 98.8."

"Do you have Ativan there?"

"Yes," I said, though I had utterly forgotten it, in my rush to use the Roxanol.

"Some of the symptoms may be anxiety from the heart attack. So give her the Ativan."

Several weeks earlier, our nurse had explained how and when to use this sedative, assuring us that it would be okay to take even two of the small pills in one night.

"Okay, I'll give her one. But I need to know one more thing. . . ." I paused. "How much Roxanol can I give her?"

"Don't be afraid to use the Roxanol."

That was exactly what I needed to hear.

We controlled the first episode of her attack with just 30 mg of Roxanol. In the six weeks since mother had been discharged from the hospital, this was only the seventh night that we needed to draw down from the little bottle. Nevertheless, had this medication not been available throughout this period, we would likely have found it necessary to dial the dreaded 911 each and every time.

The severe bouts of pain always made their appearance during the night—and this even with a foam wedge to keep Mom elevated as she slept. She had been discharged from the hospital, had been seen by her doctor, and yet it was only when the hospice nurse first visited that we learned that a wedge would reduce the night pains. And hospice, of course, supplied the wedge. It worked beautifully for awhile. Previously,

Mom had resorted to spending the night in the easy chair. But now even the wedge could no longer assure her of a peaceful night.

At the end of episode two, after we had controlled the pain with 60 mg of Roxanol, Mom decided she wanted to move to the easy chair in the living room. The fascinating thing about morphine, I had been told weeks ago by our hospice nurse, was that as long as there is pain, the medicine goes to work directly and only on the pain center in the brain. It does not impair judgment; it will not cause hallucinations. So, what should I make of Mom's request to change rooms? Would walking be advisable? Would it even be possible?

I called the nursing staff again.

"Yes, she can try to walk out to the living room. Make sure the pain is controlled, and give her some orange juice first." The nurse then told me to walk behind Mom, with my arms around her waist, and what to do if Mom began to fall.

"Remember, Mom, the morphine is only masking the pain. You are still having a heart attack. So let's be very cautious." We waddled out together into the living room, like a pair of penguins attached at the waist. Mercifully, the little house was perfect for the elderly. It was a single-floor, ranch-style home. Only one stair separated the front sidewalk from the porch and only one stair set the kitchen apart from the garage. The basement had been inaccessible to Mom since her hospital release, but that was okay as I was doing the laundry now.

It was, in fact, a lovely little house. Small enough to keep one from feeling too lost, too lonely. And she had been in it for twelve years. It had started out as home to three, then two, then four (when her son returned home with Kendall), then three (when her husband died), then two (when Kendall's father went to live with a girlfriend but left his daughter with Mom), and now two again: Mom and me.

During my first trip to Michigan after she had had fought her way out of the hospital, I had decided to give Mom the benefit of the doubt. There was no need just yet to discuss with her the unwelcome prospect of having to move into some sort of an assisted-living facility. If Mom believed she was going to die, then I would simply stick around until that happened—or reassess the situation six months later. Not being a mom myself, and earning my living as a freelance writer and editor, I was free to make the move. My husband, a hermit at heart, would accommodate—gladly at first, though six months seemed a little excessive to him.

She had waffled a bit on her sense of impending death, however. During the night attacks, death, not surprisingly, seemed imminent. But, except for the day after such a

night, she seemed far from death. Well before I would stir, she would be up and about the house, albeit at a muted pace.

"I'd like to die September 11," she announced one day. That was when her own mother had died—at home, in her sleep, at the age of 74.

"Well, maybe death will accommodate," I responded. We had made a pact during my first visit. She could decline anytime except during the ten days I had to be in California for very important meetings. Other than that, the schedule was open.

"Will you help me put up the Christmas tree?" she asked when I told her I would actually enjoy spending Christmas with my own side of my family—something I hadn't done since high school. Christmas these past nine years had always been spent with a portion of my husband's huge family in New York or New Jersey, and that family had come to feel like my family too.

Mom's and my shared living ended, however, long before Christmas. She died July 24, six weeks after her discharge from the hospital. I wonder sometimes now whether she had orchestrated the timing by more than sheer will. Kevorkian would not have been her style, but she did have a few tricks on her side.

Notably, she knew that it was a little too much yard work that had put her into the hospital a few weeks earlier. This is the explanation she had given me and that she said she had told her doctor.

The evening of her death she sat on her little footstool, picking chips out of the grass, as I scraped curls of paint off the deck and rails—a project that was years overdue and that had been instigated by my Seattle brother-in-law the previous week during his visit. Once you start scraping a deck, you do not leave the project unfinished. We were committed. At dusk she urged me to quit and go for my evening walk. "I think I overdid it," she confessed, palm to her heart.

"Let me get you a nitro," I offered.

"Oh, those stopped working a long time ago."

I insisted we try, and there was soon surprise on her face. "It worked!" I was off for my walk, while she remained on the deck, as she often did, to watch her bed of evening primrose explode into bloom.

My evening walks always culminated in a leisurely swing at the school playground. As long as I had my walk and my swing, I judged the day satisfactory. It had been almost thirty years since I spent a summer in Michigan, enveloped in the lush, balmy, green-rich evening air, and I was enjoying the opportunity to call up childhood memories, drawn out as well by the very business of living "at home" once again. The

tupperware—though battered—was still in use, as was a faded blue porcelain mixing bowl that carried me back to even earlier times.

Save for higher standards of housekeeping, Mom is exceptionally easy to live with, and I suppose I am too. We got along splendidly. And she taught me something, by example, that I had forgotten—that life was an end in itself, not just a means (for the writerly me) to create. Scrabble and Rummikube were more than just evening diversions out on her deck; simple, purposeless pleasures in companionship were at the very core of life.

I had rescheduled once already my return flight for a brief visit back to my own home, and was on the verge of extending my departure date again. My sister's husband, whose Seattle home was a long way from Michigan, had volunteered to do some business in Detroit while I was away, staying with Mom. One of my brothers, in Midland, Michigan, had planned a week's vacation to Gettysburg for his own family of five, which would be coming up in just ten days. Under no circumstance would my mother want to disrupt that family event with something as inconvenient as her death. It would either have to be now, or a good deal later.

The previous two weeks had been a whirlwind of family gatherings. My sister and her family of three had flown in from Seattle—an annual summer visit that had been scheduled even before Mom's sojourn in the hospital. And because I had Betsy's assistance in the car, I was willing to tackle the two-hour drive that would take Mom up to Midland for a final visit.

That visit was lovely. Mother made clear it would be her last, but without being morbid in the telling. By then, many of us in the family, certainly me, had even begun to playfully mention death, as in "Well, I guess you won't be needing this anymore."

Mother and I had years earlier talked about my getting her shoes—including one pair I had bought for myself but had given her when she discovered on one of my visits that they accommodated a troublesome toe better than any of her own. And I was delighted, a month before her death, to discover I could wear her bras too, some that she had worn when she was my age and had long since retired, but had kept nevertheless. On the day of her memorial service, I wore her shoes, her dress, her jewelry, her lipstick, and her lingerie. I explained my newly acquired clothing to the congregants, as I shuffled the papers to read her biography (finished, with Mom's assistance, just three weeks earlier), "I came prepared to take care of Mom, not to attend her memorial service. So everything you see, and even something you can't see, is hers."

One by one, mother and I had worked through her "to do" list. We had been through the lingerie drawer. We had been through her Christmas list and crossed off the

names of people who had slipped out of her life—most by way of death. We had sifted through everything in the strong box that contained the will, the financial papers, her husband's death certificate. We had been through the schedule she keeps of when payments for this and that are due.

I still have that "to do" list. All items, save one ("fix chandelier"), all written in her luscious script, have been lined out. Her business was complete and her visits had been full and rich (even a reconciliation with her younger of two sisters, after many years of estrangement), so there was nothing left to do, really, but die at a convenient time and in a way that would allow me and the Roxanol to provide her with the comfort she desperately wanted, all in her home.

"I love this little house, Con," she told me when we had the pain controlled during episode one of the final night. "I want to die in this little house."

My brother found her ring on the night stand the next day. This way we didn't have to retrieve it from the funeral home—as there was no way I would have thought to remove it after she died. Mom had thought of everything.

Four or five days before her death, I had stopped nagging her about overextending. I stopped protesting when she started the dishes or headed out to the mailbox. I stopped saying, "Let me do it, Mom." I stopped reminding her to hold on to her chair for a few seconds before rushing off—as the nurse, alarmed at 98/58 blood pressure readings was worried about a fall.

"You can do anything but break a hip, Mom," I assured her. "You can have a stroke, you can have a heart attack—anything but fall."

My mother did not want to be bedridden; she did not want to become a burden. With hospice, we knew that even with a stroke, there would be no feeding tubes. And even for lesser problems, should she be confined to bed, we knew she had an option.

"What if she gets to the point where she can not or will not administer her insulin?" I had asked our nurse during one of her visits.

"Then it's up to the caregiver to either administer it or not."

"And what if I don't?"

"She'll likely be in a diabetic coma within three days."

"There, Mom, nothing to worry about!" We all laughed.

Mother and I had discussed such matters from time to time, in bits and pieces. It all began three years earlier during the previous (aborted) hospice adventure.

"What do you want to have done with your ashes, Mom?" I asked her then.

"Well, I hadn't really thought about it, but Grandma Barlow had bought me a grave alongside your father's, and I suppose I can still use it." The urn of my mother's

second husband was conveniently buried atop the grave of his long-dead first wife, so there was nothing scandalous about my mother's suggestion.

"You know, you don't have to be buried at all," I ventured. "Lots of people simply have their ashes scattered in a favorite spot." I continued, "You know those white birch trees Up North that everyone calls Grandma's birch trees. . ."

"That would be lovely, Con. I want to have my ashes spread there." Her smile was beautiful and she was light-hearted the rest of the evening. As I recall, she even hummed a tune the next day, something she did a lot when I was a child but that I hadn't heard for many years.

Two nights before her death, Mother and I had a final chance to confirm our agreement about what to do if she was not able to direct my actions. PBS was running an independent film on hospice in its "Point of View" television series. Mom and I watched the program, riveted to the screen, calling out in unison, "Don't do it!" or "Just say no!" when a patient or caregiver was given the option of a feeding tube or a respirator or some such life extender. After it was over, she told me, "Con, those two elderly people: I never want to get to that point." That point was bedridden and extremely enfeebled.

"Gottcha."

Enfeebled did become a worry for her, as it turned out. During episode two, before she had decided to attempt a walk to the easy chair, she was sitting on the edge of the bed as the morphine kicked in. "I just know I'm going to be useless," she sighed. I said nothing. At that point, it simply hadn't occurred to me that she would be dying that night.

It wasn't until episode three, the final episode, and then not until that stage was well under way, that I really began to think she was dying then and there. I had some time to reflect on such prospects, in between attacks, but death had not seemed imminent. Reflection was not, however, what I wanted. I wanted to relax, to think about something else. And so, once I got her settled into the easy chair, with a wet cloth on her forehead and a fan pointed in her direction, I raided her bedroom.

The only medicine I wanted, however, was a stress reduction tape that I had brought with me on my first visit after she was abruptly released from the hospital. My husband's sister, a hypnotherapist, had made the tape, using studio support and New Age music as background for the recording. I had played the tape many times in New York to set myself up for restful sleep after a stressful or excitement-filled day. But I was open to such novelties; I was adventurous. Mom was generally not, and so I offered it to her somewhat sheepishly, just to try.

She loved it, and asked for it every night that she was not exhausted upon retiring. We started to refer to it as "the clouds tape," as we agreed that the loveliest imagery in this tape of guided imagery is Kris's soft suggestion that we imagine ourselves resting on "a beautiful white cloud." The temperature is perfect, the sky is blue, and "you feel so good."

I settled into bed, rewound the tape (Mom had been halfway through the tape when her attack struck), but could not in any way conjure up clouds. Not far into the tape, I heard the tinkle of the bell—for the third time that night. Some years ago she had purchased it through a catalogue, with no particular use in mind. The crystal bell had served us admirably this night, as it had a half dozen prior nights. The bell made beautiful what would otherwise be wholly unbeautiful events. Like the bell, death, we both hoped, would in some way be beautiful too.

What greeted me upon entering the living room was far from beautiful. She was clearly in agony, agitated, leaning back in the chair and then sitting up, trying without success to find a comfortable position. I administered a whole dropperful of Roxanol (about 25 mg) right away. How could I wait twenty minutes to see if that level was enough? I gave her another dropperful, scribbling on a slip of paper the amount, as I had begun to do during episode two.

I helped her sit up; I helped her sit back; and then I helped her sit up again. I turned over the cloth on her forehead; I reached for the other moist cloth and pressed it where she pointed: against the sole of her foot. I found ways to be busy. I would assure her that the Roxanol would be working soon—that we could do it—and then I would assure her again. I gave her another dose of the medicine, and I assured her again.

Finally, I told her I loved her.

She looked up at me with a beatific smile, then went back down into herself to resume her struggle.

I'm not sure anymore that it was pain she was wrestling with then. I think it was more an alien feeling of the body going haywire, of organs shutting down. Either way, I can say she was brave. She had determined to die in her lovely little house, and she did just that. The only thing she said, during all of episode three—besides trying convince me in a combination of words and gestures that a cloth really did need to be pressed against her foot—the only thing she said was, "Lord take me." Maybe twice. Then the morphine kicked in, or maybe this would have happened anyway, but she just stopped fighting. She eased back into the chair, eyes almost closed.

I knew she was still conscious. I knew she was conscious because some time into this quiet phase, after I had knelt alongside the chair and started talking softly to her, my

right hand stroking her forehead, she ever so slowly, ever so gently, lifted her right hand. It had been crossed over her stomach, but now she extended it in my direction.

She had many times spoken of three wishes for her death: no hospital, no pain—and someone to hold her hand. I clasped that hand with my left, and continued talking gently, running through a litany of names of who "loves you," as if it were a holy last rite. Then repeating, and repeating. As her breathing became intermittent, I talked of the clouds. I talked of the beautiful white clouds that she would soon be joining.

Her slide into death was so smooth that I was not sure exactly when it happened—even *if* it had happened. But at some point I let go of the hand, kissed her on the forehead, and retreated to her bedroom where I called my husband to unload. I was not yet ready to disturb my siblings until I was absolutely sure. I called each, in turn, maybe an hour or so before I knew they would be up readying for work. There was no rush. At dawn, I took a walk along the same course I follow in the evening. This time on the swing, the pink clouds—the lovely pink clouds—were in an unfamiliar quadrant of the sky.

At 7:30 I called our skilled care nurse at her home. When Marianne arrived, she stood for awhile gazing at my mother, at my beautiful mother sitting peacefully in the chair. Marianne said nothing during this time; she simply stood in the exalted presence of the beautifully, naturally dead. Finally, she bent down for a moment or two to do the checking that would confirm the judgment, then we moved to the kitchen table, just a few paces away, and got down to business. Soon, Deb (our social worker) arrived. She walked me through the options for funeral homes, and even made the call in my stead. For much of what ensued, however, I was not needed. Marianne and Deb could take care of things. More, I did not want to be in earshot when Marianne called my mother's doctor.

"Just tell him she had a severe case of arthritis of the chest last night," I said as I headed out to the deck, where I slid into a chair facing the soothing, low-angle sun.

This one instance of bitterness aside, I can say in hindsight that the death and its immediate aftermath were far more satisfying than sad—dare I say thrilling? Through hospice, the experience of death acceptance and mourning happens over an extended time, beginning well before the actual death. And there is a real chance to find beauty throughout. I learned, too, that partaking in a death, especially a natural death of a loved one who has lived a long life and is at peace about the end to come, is a privilege indeed. I know my sibs were deeply grateful for my services, for my ability to make Mom's wishes come true, but I suspect that more than thankful they were envious.

I know, too, that I was able to offer my services, to accept this gift, only because our society has authorized the hospice philosophy to serve as a sanctioned and insured alternative to the hospital philosophy. I learned how well hospice can help a patient and a family find death a rich and rewarding experience—psychologically as well as medicinally, for the caregiver as well as the client. Our family was not able to receive all the hospice services, as, remember, Mom's doctor had removed her—us—from hospice. We weren't able to call on the bereavement services, for example, which would likewise have been covered by insurance. But because of our hospice experience, bereavement services—thankfully—would not likely have been called upon.

On the dark side, I learned, too, that our society has not yet made it possible for the passive among us to achieve a wished-for natural death at home. One does not necessarily find out about the hospice alternative by way of the doctors we depend on throughout our lives to keep us functioning. And even if one does hear about hospice and expresses a desire to follow that path, there may be substantial resistance among professionals who view death—even death of the elderly—as a medical failure.

Then, too, unlike cancer patients, heart patients that are not yet bedridden are notoriously difficult for a doctor—any doctor—to diagnose as doomed within six months, which is the certification that must be given in order to secure Medicare and private insurance support for hospice services. Our society has not yet made it possible for those who *feel* death is imminent but who can't prove it to obtain the peace of mind that, when the time comes, there is a number to dial other than 911, that there will be a little bottle of something on the night stand to ease the slide, and that a trained family member or a nurse can be accessed instantly to provide whatever support may be needed.

But it has only been weeks after the death experience that I have come to think deeply about such things. In the immediate aftermath of the death, there was only the one death and only my own emotions. There were no broader issues. Curiously, mourning was not at the top of my "to do" list. Celebration of a life beautifully, naturally ended and lovingly lived seemed more in order.

The celebration actually began when the police officers arrived that first morning, as they must to ensure that a death in the home was not a "wrongful" death. Marianne spoke with the two of them for a long time before one stepped out onto the deck. Praise for hospice gushed out of me as soon as we made eye contact. And that, in turn, was all he needed to launch into a recitation of his own very positive experiences with hospice—and the contrast of what happens when a family, not under the hospice wing, panics and calls 911.

"It's awful. I tell the family that I would never want this done to me, but nevertheless, I'm legally required to try to resuscitate."

I told him that my mother had made precisely that mistake when faced with the death of her late husband, his cancer-wracked body finally succumbing at home. The chaos that ensued convinced her that there must be a better way.

We walked back into the living room, where I met the other officer and chatted a while. Then, as they began their goodbyes, we all stood for a moment admiring my mom, who was still resting comfortably in the chair right next to the front door. By the time he departed, officer number one was beaming.

"This makes my day!" he said. "This just makes my day. A death in the home exactly as it should be."

The celebration would continue, blending with mourning, in the memorial service. Mother and I had done a bit of preparation for the service before her death. And I rapidly began building in more components. She had a number of favorite prayers to choose from that she had clipped from her church programs and pasted onto flowered stationery. In conversation a few weeks earlier, she had specified one hymn, to be printed in her memorial folder as well as sung: "Savior, Again Unto Thy Dear Name."

A brother, a sister-in-law, an aunt, and myself easily came up with four other hymns that we knew she loved and that we loved too. I, of course, was already equipped with her "approved" biography, which was more than just the facts. For each phase of life I had asked Mom for a direct quote, some single remembrance, that would give her personal touch to the reading. On first meeting my father, for example, she recalled, "He asked me to dance; he was a wonderful dancer!"

Her minister counseled me wisely, upon hearing how much we already planned to do. "You don't need me to officiate. We Congregationalists believe that you can be in the presence of God without clergy. It sounds to me like your family is fully capable of performing the service themselves."

Yes! If we could do death ourselves, then surely we could handle the remembrance.

"But what about the Catholics in the family?" I asked, worrying that the Kelly side of the family—my step siblings—might object.

"That may be difficult. But I urge you to try."

The room in the funeral home was more than packed; people were spilling out into the hallway. I had spent the previous four days planning out the service, with the advice and consent of family—both sides of the family. This was to involve the whole crew—all

four of Helen's children, the four stepchildren, plus spouses, grandchildren, my mother's dear sister and her two children, and two long-time friends. This service called for a script with twenty-seven parts. Those who wanted to talk would read one of Mom's favorite prayers or tell a story. Those who knew they would be basket cases would need do no more than walk up the aisle in the opening procession, carrying one of Mom's favorite objects—her sacred objects—with which to embellish the altar.

Those who volunteered to do more than the minimum found the preparation for their role comforting, redeeming. It transformed grief into positive, beautiful action. My sister, stuck in Seattle, was called in early to take charge of disassembling Mother's bedroom, deciding what to keep, what to toss, and tidying up her lovely blue room so that all the women and girls in the family could go in there the morning of the service for our final preening, perhaps choosing a piece of jewelry to wear, daubing on some of mother's (or grandma's) perfume. Betsy had been having a very difficult time coping with Mom's death at such a distance, but she charged into her assignment with gusto and thereby was healed.

She created a second job for herself too, which kept her working until dusk the evening before the service. Half of Mom's evening primroses were transplanted into pots, for anyone who wished to take them home. Mom's "small miracle" could thereby continue to be enjoyed by loved ones for many years to come.

My stepsister Shirl took charge of obtaining storytellers from the Kelly side of the family and listening to my suggestions for ritual. She herself planned to talk of Mom's talent for merging the two families. Kendall's father and a stepbrother, Pat, were in charge of getting the food and renting the tables and chairs and canopy for a post-service reception. My aunt was assigned the responsibility of constructing the photograph board for the youthful phase of her sister's life. My Midland brother and his family made a most artistic collage on the photograph board that chronicled Mom's visits Up North on the family property—including the pictures we had taken over the years of Mom with her beloved birch trees. In the week before the service, Bill visited those trees again, this time intent on taking the photograph that would be used on the altar, to set in front of the box of ashes. And he himself would carry that enlarged and framed photo in the opening procession.

Even the youngest grandchildren had important tasks. Toward the end of the service, they were to distribute to all the congregants the contents of one of the altar objects—a glass vessel containing stones my mother had collected and polished—while Pachelbel's Canon in D was played. None of Helen's children had quite seen the beauty

in those rather ordinary stones during the many years that she had collected them. But in this context, they became utterly precious.

In addition to reading the biography, my role was to carry in that vessel of stones. When my turn came in the procession, I carried those stones with pride and serenity, taking full strides that matched the slow rhythm of the symphonic music we had chosen, comfortable in Mom's cream pumps. But after I sat down, the tears erupted when I watched Betsy struggle to place a rose into the vase on the altar. She had clipped the rose from Mom's garden that morning. Michael (Kendall's father) had carried in the vase, her partner in the procession. The two stood at the altar for a long moment, his arm wrapped around her shoulder.

Three of the older grandchildren took on the toughest tasks. Colleen, soon to enter her senior year in high school, read the opening prayer immediately following the procession. Two other grandchildren, age 11 and 12 and fast friends as cousins, shared the reading of the final prayer, which they performed with utter grace. No adult could probably have survived that task, as I had rewritten this prayer of praise and gratitude a wee bit, to include Mom's favorite things.

"Gracious and loving God," it began, "the one who has made the heavens and the earth, the one who has surrounded each of us with beauty and goodness, help us see what You have made, and to fall down before You in wonder. Let our hearts open before You"—and here comes the rewritten passage—"like the yellow blooms of evening primrose at the approach of dusk. And when our time has ended, may we bestow upon our loved ones the richness of memory that will surely well up unexpectedly from time to time, in the rustle of wind through trees, in the fragrance of a rose, in the colorful arc of a rainbow."

My mother's sister, Aunt Marge, heroically volunteered to create and read a farewell, as if my mother were speaking, followed by the benediction. She, too, performed her part magnificently, though her voice would sometimes quaver. When I saw her looking directly at me during one passage, I collapsed into tears. But she maintained, as she had a job to complete.

There was to be one more goodbye after Marge's, one more chance for catharsis. This time it would be Helen herself speaking. Betsy's husband, Bruce, who had been emceeding the whole event, prepared the audience for what was to come and then turned on the three-minute clip of tape.

Three years earlier, following her previous brush with death, I had recorded Mom in discussion with various segments of family, leisurely working our way through family history. Although she had married into the Barlow family and so wasn't an ideal source

of Barlow family history, she was the only one left of that generation. And so, on a trip to the home of my brother Bill, who had inherited the Barlow family bible (going back six generations, each generation recording marriages and births and deaths in its own hand), we sat around the diningroom table, probing our collective memory of my paternal grandparents, how and why the Up North property had been bought, Mom's experience helping build the first "shack" (which had long since crumbled) and inaugurating the tradition of planting pine trees.

At the end of our conversation, she had told a funny story involving my sister and me, perhaps then age three and two. I had always enjoyed her laugh, her unusual but lovely laugh, and this tape displayed it perfectly. So for the memorial service, we cued up the tape to the beginning of the story, after which came all our taped goodbyes, directed playfully at future listeners. Mom's voice came last, just a soft and simple "Goodbye."

Because the storytelling and the tribute to hospice had been so popular, and our service uncharacteristically long, the organist had to leave before the final hymn. "Amazing Grace" followed on directly from the taped goodbye, and it became a haunting (and in some parts of the room, wailing) a cappella, as we deconstructed the altar and blew out the candles.

One very sacred object had not been placed upon the altar, however. We kept it among us to ring out the beginning, transitions, and end of the service. And when the time came to distribute my mother's possessions among family members (many such disbursements, of course, had already been specified in her will), there was no question as to who would come away with the crystal bell.