

Faith @ Work Article

DYING WITH DIGNITY
by Klara Tammany

Today as I begin to write, would have been my mother's 79th birthday. This summer, my brother, my sister with her husband and two children, and I plan to put Mom's ashes in the woods at our summer cottage on a small lake in Maine. She will join four cats, Itty Bitty, Steve, Smarty and Dumbell; a dog, Taj; and my Dad. The informal family plot is on a rise in the "mini-forest" that lies between our house and the road. The place marks not only the final resting spots of these loved ones, but tells of a family journey of discovering dignity amidst great loss.

Dad died in 1996 after a thirty-five year battle with Parkinson's disease. In his final few years, as is typical in advanced stages of the disease it began to affect his mind, with symptoms resembling Alzheimer's. After a traumatic experience of a nursing home for Dad, we as a family, committed to making it possible for Dad to stay at home until he died. For three decades we had loved and lived together through the progress of the disease, including the early treatments of multiple brain surgeries and experimental drug trials, and witnessing Dad's struggle to keep going against all odds. We could not do otherwise than to continue his care at home. And so to meet the growing demands of his care, I moved home to help Mom. Two years later, Dad died there in his own bed, under Hospice care. It was not an easy time, but except for a few instances of lost tempers, we had few regrets... that is, until after he died.

The funeral home was called to come and take Dad's body away. An hour

or so later they appeared, placed him on a gurney and zipped him up in a bag. He was clothed only in undergarments. It was an undignified, cold and harsh parting. The sacred was hidden, no pause, no prayer. It felt as if Dad was ripped from us. As they wheeled him out, Mom stood in the living room with fists clenched, wailing, “I don’t like this! I don’t like this! I have done everything with him. I want to take him all the way.” She did not want to let go of Dad’s care just because he had died. It was as foreign to her as another language, literally I now realize. Mom, you see had come to this country after WWII from Hungary. In her culture, things had been done differently. At the time however, there seemed to be no alternative to our American way of dealing with the dead, but to watch. There was a huge void from that point until Dad’s ashes were returned for the memorial service. We had absolutely no involvement or control over what would happen to his body until the urn appeared for the memorial service at the church. Mom met with the undertaker the next day to sign papers. Soon after came a nearly \$2000 stinging bill – for the \$850 up front “non-declinable fee,” the transport services, the urn (we now know we could have supplied on our own container), and cremation. After it was over, Mom proclaimed that never again did she want that to happen in our family.

The husband of a friend of mine died that same month. We shared our stories. Mine was a one of frustration and loss. Sandy’s experience with Paul’s death was personal, tactile, gentle, loving, unhurried. A wise crone in her Maine village, Sandy and her friends, recovered the old ways. Until two or three generations ago, she told me, families and communities, not funeral homes, tended to bodies after death. A death was “mid-wifed” just like a birth, usually by women. Communities, churches and otherwise, supported

it. Only in the last generation or two, had caring for the dead become a mostly male run, profit making industry, taken out of the hands of home and community. I learned from her that for those who wish for something other that is more personal, there indeed are legal alternatives to the funeral industry. Although most of us have forgotten how to be with death, she said, we could regain what we needed. It was time.

About ten years later, Mom was diagnosed with a rare and fatal blood disorder. In the intervening two years before she died, she planned how she wanted to die and talked with us about it. When the time came, she would not take any extreme measures to prolong life. She wanted to die at home. And she hoped we could do the funeral ourselves. From Sandy and others, we learned what we needed to know. As her condition worsened, with the help of Hospice, Mom's friends from her church and neighborhood lovingly shared with us in Mom's care. The night she died some of those friends were with us. We sang hymns and read psalms to Mom. When her breathing changed, I began to sing one of her favorite pieces, one she requested for her memorial service, Mozart's *Ave Verum Corpus*. In the middle of it, she stopped breathing. Several slow moments later, we turned off her oxygen and called Hospice and Sandy to come and help us. When Sandy arrived, we lit candles, washed Mom's body and put on her favorite nightgown. A friend, Bill came in the early morning with a simple casket he had made. We laid it on two sawhorses in the dining room, placed Mom in it, covered her with a home quilted lap robe and draped a linen cloth over her face. We set up an altar of memories in the room, each family member contributing what was meaningful to them. Friends came to say goodbye. They were invited to bring cuttings from their gardens to place in the casket,

and they did. While there they wrote messages on the inside of the casket lid. An artist friend drew the Duomo in Florence, Italy, a place Mom always wanted to visit. It was a two and a half day vigil in the manner of an old fashioned wake. We shared food and memories, we laughed and cried. One friend was designated to go around town to get the death certificate and needed permits. Using someone's van, we transported Mom's body to the crematorium, driving by our cottage at the lake on the way. Once there, we prayerfully sent her away. A memorial service was held at the church a few days later. It was a grace-full time of re-membering and of holding each other in sadness and thanksgiving for a life well lived.

What a difference a few years and a bit of knowledge makes. With Dad, our experience was one of uninformed consent. With Mom, it was one of compassionate choice. I would rather the latter, for everyone. Some of the friends who helped us have said they want to die the way my Mom did, gracefully and with dignity, and in control of the end of life. The experience has led me to want to do two things: to work with those who are dying and their families through a ministry of spiritual direction, and to find ways to teach others how not only to care for loved ones while they are dying, but to care for their bodies after death. I am doing everything that I can to explore and prepare, and pray the vision through. This past year I volunteered for Hospice, and have participated in workshops on death and dying and palliative care. I am reading a lot and have enrolled in a program at Boston College, to immerse myself in the study and practice of spirituality. This fall, I will begin a CPE unit, hopefully with a focus on palliative care. I hope to then attend a program offered by the Alaya Institute.

It has been a steep learning curve – challenging and fascinating. In a

thanatology class that I audited last spring, after showing us a very personal video that someone had made about the death of their mother, the professor pronounced “As you can see from this film, there is no dignity in death!” The professor’s comment was spoken firmly and surely. Then he walked out of the room. Professor, wait! What do you mean by that sweeping statement? Why do you say that? Can you define your use of the word “dignity”? I begged to differ, but there was no opportunity to do so. Given the chance, here is what I would have said: Yes, our culture’s way of death unfortunately does not often contain much dignity, but it doesn’t have to be that way. Traveled with intention and in community, great dignity can be brought to our last journey, no matter what the circumstances. I know. I have learned so bit by bit, from wise friends, and from experience. It is a process of recovering an old wisdom. The good news is that things are changing. Awareness of Hospice and palliative care is on the rise and our society is at least now talking about living wills and medical powers of attorney. But there is much more to consider such as ethical wills, home funerals, and green burials. And it is time for churches, synagogues, and other religious communities to take back more of the role of supporting those who are dying and their families, including care of bodies after death. There is a growing movement in this direction. Although I have no clue yet exactly how or when, I know I will be part of it. Many remarkable affirmations of the call have come my way on the discernment road this last year, too many to ignore or dismiss. Something is being born.

Dig-ni-ty *n*

1. a proper sense of pride and self-respect
2. seriousness,