

"Here I Am, Standing Right Beside You"

Spiritual Accompaniment and Care of Alzheimer's-Impaired Parents

Janet K. Ruffing

A few months before my dad was diagnosed with metastatic colon cancer and when his Alzheimer's was already well advanced, I was with my parents and Dad's caregiver, Natalia Crook, at Eucharist in our parish Easter Sunday morning. During the communion procession, we sang Tom Booth's song, "Here I Am," which I was hearing for the first time. I dissolved into tears and into God, recognizing, deeply, how Jesus had been standing right beside me, beside us as a family in the entire circle of caregivers, who became part of our journey as we cared for my dad and subsequently for Mom.

At that time, Natalia Crook had been caring for Dad twelve hours a day for about two months, accompanying Dad minute-by-minute through his day and standing right beside him, bringing order to his day by guiding him through every moment and, as a result, calming his anxiety and bringing some peace to the household. She, too, was deeply moved when I was, and sensed what I was feeling as well. Intuitively, I also wondered if this was to be our last Easter with Dad, which it proved to be. For us, the

Janet K. Ruffing

meaning of the verses of the hymn seemed to have a powerful spiritual effect.

Here I am, standing right beside you. Here I am;
Do not be afraid. Here I am, waiting like a lover.
I am here; here I am. I am here.

Do not fear when the tempter calls you. Do not fear even
though you fall.
Do not fear, I have conquered evil. Do not fear, never
be afraid.

I am here in the face of every child. I am here in every
warm embrace.

I am here with tenderness and mercy. Here I am; I am here.

I am here in the midst of every trial. I am here in the face
of despair.

I am here when pardoning your brother. Here I am;
I am here.

In the compressed moment of communion with the Risen Christ, the parish community, and my parents and caregivers, Christ was everywhere and "standing right beside me." I knew I could trust that he had been and would be with me for the whole journey. And I trusted that he was present "with tenderness and mercy." It seemed to me that Dad's experience of Natalia was of her standing right beside him during his waking hours, in a very loving way. Theologically, in the terms of the song's image, Natalia had become a Jesus-presence, standing right beside Dad. When in our shared faith we talked about it on the way home, I discovered that she too recognized herself in this role.

As a family, we had always been faithful Sunday Catholics, participating in Eucharist with the parish community. By Easter Sunday 1999, my parents had been worshipping in the same parish church since 1960. Relatively recently, the church had been reno-

vated, placing the altar in front of the original sanctuary on a raised platform, and the pews, removed from the nave, had been placed on either side of the altar. Four pews thus faced one another with the altar between them, and the first row on one side provided seating for the altar servers and on the other, for the handicapped and infirm. The weakest in the community were thus seated only a few feet away from the altar with a completely unimpeded view of the presider. Eucharistic ministers brought communion first to the handicapped and then to the rest of the community. Others who came in the front side doors filled in the rest of the seating. Often, they were the families of the lay ministers for the service. In this way, the ill and handicapped were cared for and included within the worshipping community. For many, such as my parents, they had never been as close to the sacred action before.

For my church-attending parents, the eucharistic ritual was utterly familiar, and, despite being ravaged in other ways by their dementias, they continued to respond to the entire ritual. It seemed to me that for both parents, liturgical music communicated as much as, if not more than, the reading of Scripture and the homily. The sung music, with its theology embedded in its words, touched their hearts and the intact parts of their minds, and they were always totally present and visibly connected to the service. Somehow for them, the kiss of peace reinforced the affection among us, and the holding of hands at the recitation of the Lord's Prayer joined us to the larger community as well as to one another. These embodied ritual actions may be for such patients a significant access to God and to prayer throughout their illnesses. For me and for our Filipino Catholic caregivers, it was as well a consolation.

Natalia and her husband, Leo, continued to take Mom and Dad to church every Sunday, as long as it was possible. In addition, the local parish had a team of lay ministers who brought communion to the homebound, and when Dad was brought home from the hospital after his cancer surgery, we arranged for one of them to make a weekly pastoral visit to my parents, including a communion service. As the adult daughter and the one responsible for oversee-

ing my parents' care, I discovered over and over again that I had to make the request from the parish when I was in town and make church attendance an activity I expected the caregivers to provide. It helped that our caregivers were members of the same parish.

By September, I had taken a leave from the university in order to be with my parents in California more consistently. When I arrived home, Natalia told me that sometimes my dad would call her "Janet," and on one such occasion, she reported that Dad had said, "Janet, I don't know how much longer I can keep on going." This was my first experience of Dad's "nearing death awareness," despite his severe dementia. By the time I returned from retreat ten days later, Dad was in the hospital and had been diagnosed with metastatic colon cancer that had already reached his liver. They gave us a prognosis of three to six months.

Dad's dementia made his hospital stay something of a nightmare for him. He had to be restrained and was black and blue from pulling against the restraints and resisting care because of his confusion and fear. Mom, by this time, was already showing signs of moderate cognitive impairment and was functioning far below her normal level, given the impact of Dad's diagnosis on her. At this point, I spent mornings with my Dad in the hospital and interacted with the medical staff, and Natalia helped my Mom at home. She then brought Mom to the hospital in the afternoon and stayed with Dad, so he was not left alone so much in the hospital.

Before Dad's surgery, we arranged for a priest from the parish to administer the Sacrament of the Sick. I requested the priest whose grandmother had Alzheimer's and who, I knew, would be comfortable with Dad's dementia and with us as a family, since I had already made a connection with him from Sunday worship. I had indicated in the scheduling that both Mom and I would be present and that I planned a simple service. Instead of the pastorally sensitive priest I had requested, another priest, who was obviously challenged relationally, arrived with the chrism of the sick but without communion. He said, "I didn't know if your Dad was rational enough to receive

communion." I said, "He is, but you knew Mother and I would be here, and this is part of the sacrament." The priest proceeded to say the prayers in a mechanical way. Just before he began the anointing with oil, I stopped him and said, "We need to listen to and sing a song, so Dad will know he has been anointed." I had brought a tape recorder with me and we played and sang Marty Haugen's song, "Healer of Our Every Ill" (1987). The music and the words powerfully expressed a hopeful sense of healing, comfort, and faith that extends beyond pain, fear, and sorrow. It captured the mix of feelings I guessed Dad might be having, but it also expressed those that Mom and I were experiencing and supported our efforts to move toward Resurrection-faith and a trust in God, despite Dad's diagnosis.

Healer of our every ill, light of each tomorrow,
Give us peace beyond our fear, and hope beyond
our sorrow.

You, who know our fears and sadness, Grace us with your
peace and gladness,
Spirit of all comfort: fill our hearts.

In the pain and joy beholding, how your grace is
still unfolding,
Give us all your vision: God of love.

Give us strength to love each other, every sister,
every brother,
Spirit of all kindness: be our guide.

You who know each thought and feeling,
Teach us all your way of healing
Spirit of compassion: fill each heart.

Dad became peaceful in response to the song, and Mom and I were consoled and strengthened during this time of prayer and rit-

ual together. The priest completed the anointing and left without making any relational connection with Mom or me.

Such an inadequate approach to the sacramental life in a church that claims to be sacramental at its core is too often the case. However, as a nonordained person who has been educated and trained in ritual, I found I could supply what was missing from the ministrations of the ordained by enhancing a minimalist approach to sacramental life by including all of the senses, especially music. I knew the rituals themselves and I knew that, according to numerous neuroscientific reports, music with and without words can stimulate different parts of the brain more than words alone can do. In Alzheimer's-impaired persons, such music with meaningful texts can evoke heartfelt responses that help the impaired person connect again to deep parts of themselves and can help orchestrate a less-confused response to their situation (Sacks 1985, 36-38; Jourdain 1997; Lite 2008, 53-57).

In addition to music, I found that touch was often the most powerful and calming care I could offer Dad spiritually. I did not consider my dad to be a particularly religious person. He agreed to become a Catholic because Mom would not marry him unless he did. Only when he began instructions in the Catholic faith before their marriage did he discover that he had already been baptized a Catholic. Mom was deeply religious in her whole way of being. Dad expressed his spirituality in his love for Mom and for us and in the thousand details of householding and providing for his family. He was concrete and sensate in his expression of care and affection. Often, all I needed to do was to hold his hand; many words were not needed.

The hospital staff quickly discovered that if I was touching Dad or talking to him he remained calm and would offer no resistance to any necessary procedure. As a result, the staff allowed me to accompany him everywhere in the hospital. In the surgery waiting room, with the surgeon and orderlies standing with us, I gently laid my hands on Dad and prayed out loud for him, for the sur-

geon, and said to my Dad, "Now, you come back to us." He nodded and came through the surgery pretty well.

Throughout his recovery from the surgery in the hospital and later in the nursing home, despite his severe dementia, he would have a few minutes when I was with him when he was completely lucid. At one point, he said, "I have cancer." I said, "Yes, you do, and I am sorry you have to go through this. And we will help you as much as we can." Another time while still in the hospital, he said, "I miss your mother." I explained that Mom had a cold and she could not come to the hospital, but I called her on the phone and got her to talk to him.

Another poignant moment in the hospital occurred when I walked into Dad's room. He had a wild look in his eyes and was hooked up to some kind of inhalation machine. He was agitated and breathing very shallowly. He calmed only slightly when he saw me and, as I sorted out for myself what was supposed to happen with the machine, I placed his hand on my belly and invited him to breathe with me, making it a game. He finally got the hang of it, and when the Chinese inhalation therapist arrived, there we were peacefully doing deep abdominal breathing in perfect unison with each other.

Dad had a short stay in a nursing home to get a little stronger and to regain enough strength so that he could walk a little and we could bring him home to die. We had to intervene several times in the standard procedures of the nursing home, because Dad needed to spend more time in bed than the "rules" allowed. He tended to be more confused in the dining room, and I discovered that the TV was always on, always loud, and set to channels that appealed to the twenty- and thirty-year-olds who were on the staff. The music and images were agitating and disturbing to Dad. At one point, Dad asked, "What did I do to get stuck in here?" He was interpreting his experience there as punishment. I tried to reassure him by explaining that he was sick and that we would bring him home, as soon as we could. Within a few days, Natalia and Leo agreed to work together as team, and we were able to bring Dad home from

the nursing home and initiate hospice. Dad arrived home the week-end before Thanksgiving.

The hospice team was wonderful. Once they were in place, I could receive more support emotionally and spiritually. And I could call on various members of the hospice team to work with Mom, my brother, and the caregivers. The hospice chaplain was a woman, Episcopal priest with a mixed Protestant background. I asked her to pray with Dad and to use some of his favorite hymns that he liked from revival meetings my grandmother took him to in the mining town where he grew up. On another occasion, I asked the social worker to help the caregivers and my mom to recognize and to respond to increasing instances of Dad's "nearing death awareness" (Kornfield 1998, 205-11; Callahan and Kelley 1992).

About three weeks before Dad died, we took him out in the yard in his wheelchair to show him the newly installed wrought-iron gate. He said something like "I feel lousy." And one of the caregivers told him everything was wonderful. Dad replied, "If this is wonderful, then you are the one who is crazy." When we put Dad back in bed after lunch, I noticed that his liver was quite enlarged. I was gently touching his side, and he asked me what I was doing. I explained, "Your liver is right here, and it has gotten very large all of a sudden. This is where the cancer is." Natalia said to me, "You can't talk to him like that." I replied to her, "He knows there is something wrong with his body. It isn't helpful to pretend everything is okay, when he knows it isn't."

The social worker was very helpful in addressing the difference in our cultural attitudes about speaking about the dying process. For instance, when he met Emily, the hospice social worker, Dad told her, "My name is George Ruffing" and then added something about "angels." He reported to me a series of hallucinations or fantasies that suggested death was nearing, because "people are coming for me," he said. Then he said, "I don't want to go with them. I am going to retire in two weeks. I'm tired of all this." He died ten days later. He reported seeing his dead brother, Rudy, bringing him black

boxes. Three days before his death he said, "This is going to kill me! I'm in a mess." "I'm upside down, what have I done?"

Emily took several examples that I gave her of things Dad had said indicating he knew he was dying. She interpreted these statements as nearing death awareness. This explanation and conversation reduced the tension among us, and the caregivers learned not to contradict Dad's accurate awareness of what was happening to him, even if it was expressed in his unique symbolic language.

On Christmas Eve, Mom, Natalia, and I had a very tender and moving experience with Dad. He was very animated and wanted to know "Have I paid you enough?" Dad had been an accountant early in his career, and I understood that he wanted to know that he had treated us well and been fair. Each one of us around the bed described to Dad how loving he had been, how well he had treated each one of us, that he had always been fair. Dad's face lit up and he would question us, "Are you telling me the truth?" When we assured him we were truthful, he would reply, "Well, that makes a guy feel good." This process went on for maybe an hour. At one point, I said to my Dad, "we don't know anything that you have done to us that needs healing, but if there is something on your mind or in your heart that we don't know about and that you are sorry about, just tell God in your heart you are sorry, and it will be all right." Shortly after that, Dad became quiet and Natalia did not expect him to live through the night. Christmas Day, I went to Eucharist alone and brought communion home. I talked briefly with the pastor after Mass, and I told him how close to death Dad was. He was very kind, and he came to the house Christmas Day and anointed my dad again, while I was out running along the Santa Ana River, where I worked out my feelings.

In my opinion, the dying process is such that no official pastoral care person can necessarily be present when the dying person needs spiritual accompaniment. It is often family members who are present and, if they understand the complications of dementia, they may perceive that such patients' symbolic world offers important cues to what is happening as death approaches. My dad was actu-

ally engaging in a review of his life, and he needed our help and reassurance. My leading an appropriate response to Dad's question enabled everyone who was there to participate. And Dad received an infusion of love in response.

At other quiet times during that last ten days or so of Dad's life, I would sit and hold his hand. I was usually silent but would pray interiorly or just rest in God. Dad would become agitated if I left him, even for a brief time. I could feel him pulling on my spiritual energy. It was as if our souls were communicating with each other without words. And he knew I was not afraid of what was happening to him. At another time, Dad wanted to know what would happen when he died. I told him I really didn't know but suggested that he ask his sister, Sarah, who was a very spiritual person to help him and that he would meet her on the other side. I also said something like, whatever else happened, he could trust that God was love and that we didn't know much else about it. I told him that "God is nothing but love and the love will remain—that love begets more love." That seemed to calm him. Periodically through these last days, I would sing to him the "Suscipe" of Venerable Catherine McAuley, which has been adapted for a hymn (Nieratka 1979). The words of this song/prayer emphasize a loving God in such language as "You are a God of Love and Tenderness" and "it's you (God) who must teach me to trust in your providence" with the plea "Take from my heart all painful anxiety." Singing this song of entrusting surrender helped me and my dad. I think that it helped him hold on to God's lovingness, and he was soothed by hearing my voice singing it.

Dad lingered for another week and died on January 3. He was apparently waiting for my brother to arrive, and he and his wife came sometime during Christmas week. Even though my brother is not a particularly religious person, he was able to join us around my dad as we prayed aloud some of the prayers for the dying, and family members would choose a psalm from my community office book (1998) or would say a decade of the rosary. One of the things I discovered at my father's deathbed was that

the prayers in the Catholic Prayer Books (1962) for the dying introduce many references to sin and judgment, which were not helpful in Dad's case, because he had already reviewed his life and by this time was quite incapable of sin. The prayers for the dying from the *Book of Common Prayer* (1979) were much more helpful and positive, offering reassurance and comfort.

I don't know how much this praying aloud helped Dad. None of the family had ever been present for a death, so we were not practiced in recognizing how the process was progressing. Dad was actually in pain and having trouble breathing when we first thought he might be actually dying. We needed the hospice nurse to give us a lesson on how much morphine to administer to relieve his difficulty breathing, and that made Dad's last couple of days less labored. His death was a simple gentle exhalation and we were all ready for his death and present for it.

Hospice was again very helpful. Verne, the hospice chaplain, came, even though a clergy friend had been present at the deathbed. Verne stayed with Mom as Natalia, my brother's wife, and I cleaned and anointed Dad's body with lotion before the undertaker arrived. Verne stayed with Mom and other family members until Dad's body was removed from the house and we had completed all the other necessary tasks under the supervision of the hospice nurse.

Mother's Story

My mom had been diagnosed with mild cognitive impairment a couple of months before my dad died. She had a previous history of stroke and was suffering small strokes. She had many complicating medical problems including a heart condition, diabetes, and breast cancer. Her postmortem brain autopsy also revealed Alzheimer's disease, but this was not entirely clear before she died. Like my dad, her basic personality remained intact, although she was cognitively impaired in terms of memory, executive function, and abstract thinking. She lost some of her social functioning at this time, and it

became difficult for her to make any new friends or socialize very well. She developed Parkinson's-like symptoms the last two years of her life, which responded for a while to the Parkinson's medications. With Alzheimer's disease, there is no predicting when or which particular brain function will be attacked by the plaque. This makes every Alzheimer's journey unique to the person.

Mother was a survivor of multiple medical emergencies and adapted remarkably well and worked hard to recover from each major health challenge. She managed to survive my dad for nearly four years, although none of us, including Mom, expected Dad to be the first to die. Natalia continued now to care for Mom, since it was clear she could no longer drive nor manage her own household.

Pastoral care for Mom differed somewhat from that of my dad, because their personalities were so different. Mom continued to worship in her parish community after Dad died, with the assistance of her caregivers. However, the parish was completely nonresponsive when, more than a year after Dad's death, Natalia's replacement, Cora Ferrar, requested someone to bring communion to Mom when she was recovering from hip surgery.

Not quite a year after Dad's death, Mom broke her hip. Mom had undergone many surgeries and, since it was the last week of my school term, I thought that she could go through this surgery without me, simply accompanied by the caregivers. However, the doctors had to delay the surgery for nearly a week to wait for her blood thinners to dissipate. As a result, I was with her before the surgery. Mom was agitated in a way I had never seen her before a surgery. She seemed frightened and anxious. The afternoon before the surgery, Natalia, another religious sister named Judith, Roy, an Episcopalian priest friend, and I were with her. I asked Mom if she wanted us to pray with her, which we did. All of us laid hands on Mom and prayed both silently and with a few words. She alternately closed her eyes and looked at each of us. Her entire mood shifted, and she became totally peaceful and said how grateful she was to be surrounded and held by us all at the same time.

I continued to provide communion services every visit home, which was every three to four weeks. In these services, I always included her caregiver, and we developed a pattern of using the form of a Eucharist service with a lay presider. I always used at least three pieces of religious music: an opening song, a response to the first reading, and a communion meditation song. We read the Sunday Scripture selections, and I would often make a three-to-five sentence reflection on the word and invite Mom or Cora to speak, if they wished. We included the intercessions and then began the communion rite with the "Our Father" prayer. Cora was very sensitive and helpful, in that she helped Mom make the sign of the cross. We held hands at the "Our Father" and offered one another the kiss of peace and received communion and listened to a meditation song together. During the last year of Mom's life, I took a leave from school and, in addition to spending some time with Mom every day, we did these services at least weekly. Even when Mom could scarcely speak, I asked her on one occasion, "Is this consoling for you?" She immediately responded, "You know that it is." Despite her profound impairment in speech from the Parkinsonian symptoms, Mom always entered into her God-space, an embodied sense I have had of her since I was a small child sitting next to her in church Sunday after Sunday. I could feel her God-connection in my responsive body. I believed that by including all the senses in our communion services, I was tapping into her deeply embodied memories and, through the devotional music, helping her to organize her responses.

Despite Mom's loss of her day-to-day memory from a multi-infarct process, her caregivers, Cora and Nilda, surrounded Mom with such a loving and peaceful atmosphere that Mom showed no interest in dying. There was no wanting this to end. Her day-to-day experience was serene and reliable. She enjoyed attending some performance events, films, and regular programs on TV. Mom was obviously becoming weaker and experiencing swallowing problems. She was at high risk for aspiration pneumonia. I decided that we should anoint her late that fall, because I did not think I could rely on a timely response from the parish clergy. So

when a priest friend was visiting, we celebrated Eucharist together and anointed Mom within that service. We used the prayer selections from the *Book of Common Prayer* (1979) that emphasized strengthening and healing instead of those focused on dying. Mom was quite clear in her responses that she was not interested in considering the possibility of dying quite yet.

Between that service and sometime in February, Mom was declining. She had nearly choked to death, due to her swallowing problems. When our priest friend was planning to visit us in the middle of February, I decided we would anoint Mom again, but this time in anticipation of her dying. A consultation with Dr. Bonnie Olsen, a neuropsychologist at the University of California at Irvine, explained to me that in a dementia such as Mom had the person's consciousness may not be organized enough to recognize that she is dying or that death is approaching. We again did a full eucharistic service in our home with Mom and Cora, and I explained to Mom that this time we were going to anoint her in anticipation of her dying. I explained that she was weakening, that we did not know exactly when she might die, but she would most likely die in the next few months and I wanted her to have the comfort and strength of the sacrament. Mom's eyes got wide, and she seemed to take it in. The service was moving and tender, and we all cried, except Mom.

I cooked a splendid dinner that had to be pureed for Mom, and the evening had a celebratory quality to it. And typical for Mom, we watched a video together that evening. She had no interest in talking anymore about dying, because she was now ready for a party. This shift of mood can be challenging for family members. With dementia patients, the feelings often stay intact, but once the moment is over, it's over. For family members, the shift in feelings is often very abrupt, so it is something of a discipline to stay attuned to the moods of the patients who are being cared for so as not to impose a more sustained mood on them.

Throughout this entire period of attending to my parents during their physical and mental decline, I kept the radio on the

classical music station and also brought home CDs of classical music. Mom had introduced us to classical music, when I was only about eight years old. I knew she loved this music and was uplifted and transported by it. I was also aware of the effects of classical music on the brain. So I tried to fill the house with beautiful sounds, which I hoped would also offer some consciousness-shaping form for my parents' ravaged brains. Dad would just say "turn that off," if the rhythms and tones were not right for him. Mother never indicated that she did not want the music playing.

Mother's death process differed from Dad's in many ways. She did not have the diagnostic clarity of Dad's colon cancer diagnosis and the clear progression of that disease ending his life long before the Alzheimer's process did by itself. Mother, on the other hand, had multiple, long-term disease processes. She had heart problems going back to childhood, a multi-infarct brain process, Parkinsonian symptoms, diabetes, asthma, repetitive urinary tract infections, and the effects of treatment for breast cancer two years before Dad died. She was both fragile and fiercely willful about living. We were only sure of her Alzheimer's diagnosis from the postmortem autopsy.

Her dementia protected her in interesting ways. She and Dad had been married sixty-two and a half years when Dad died. She was already suffering some mild cognitive impairment, and so she suffered bereavement for only twelve to eighteen months before her dementia restored Dad's presence to her. She would take in the fact of his death on our occasional visits to his grave, but she would be even more shocked to see her name printed on the marker awaiting her death date. At home, it often seemed to her that Dad was still present, as I also felt him to be. I finally interpreted to her that this presence was like her having the feeling that Dad was so close to her and caring about her that she did not perceive a difference between his physical presence and his spiritual presence. She nodded in agreement.

In the same way, when her short-term memory became even more impaired, her depression lifted and she appeared to be quite

content. Our caregivers were very good to her and with her. They created a reliable structure of care for meeting her minute-by-minute needs, and they were very loving. As I imagined her reality, I realized that she experienced very little distress and was pretty happy and content in her own home, surrounded by love. She had no reason for wanting to leave the planet.

Finally, however, her heart began to fail in congestive heart failure. When I placed her on palliative care, because she was too weak to take out of the house anymore, I only then discovered she had been in CHF for a while. I had been convinced previously that she had so many life-threatening illnesses that she would likely choose to die when she felt she no longer wanted to live. During these four months of her life, I was living full time in California on a research leave and seeing her every day. The family came to see her before Easter and then I told her Easter Sunday that I would be away for two weekends in a row for speaking engagements. After that, I intended to return to New York. When I left for the first event, she actively began the dying process. Although she had no pain, she had a perpetually surprised look on her face. Her neurologist told me on Easter Monday that she might die in anywhere between ten days and two weeks. She died two days after I returned from Miami.

I stayed continually at the house with her then, and would get up and sit with her if I heard her breathing change and recognized that she was awake. Her eyes were wide open and her breathing was a labored panting. On the morning of her death, after the caregiver awakened and cleaned her, I again played classical violin music and got in bed with her and held her, to both comfort her and to support keeping her head up so she could breathe more easily. Because we could not tell how soon death would come, we called her primary caregiver, who had not yet arrived. I believe Mom clearly knew she was dying, and the whole house was thick with peace. When the visiting nurse came, she said she wished she had filmed this death, so that she could show others what a home death could be like. Mom was surrounded by

me and two caregivers. There was nothing but love and peace in the whole house. Music was softly playing in the background, and Mother's breathing pattern so resembled the way a woman in labor breathes that I intuitively felt that I was Mom's midwife as she was being birthed into another life.

I hope these abbreviated narratives of this double Alzheimer's journey may be helpful to other adult children who wish to provide quality spiritual accompaniment for their parents as well as appropriate physical care. To do so, adult children need to know about and share their parents' spirituality. If there happens to be a memory impairment, as in the case of my parents, I believe that keeping one's parents present in their worshipping community and participating as fully as possible is more important than any embarrassment about their physical appearance or behavior. The richness of a fully enacted ritual has the capacity for tapping into the soul of patients and their deeply embodied ritual memory and supporting their God-connection. Only family members really recognize the unique symbolic meanings of the hallucinations and fantasies that emerge into speech. Although Emily, my dad's hospice social worker, recognized the symbols of death—for instance the "black boxes"—she had no way of knowing that Rudy was my Dad's first sibling to die. Family members, thus, have the background knowledge of their parents' life stories to interpret their symbols and to draw on other experiences that would support them in their dying process.

Within this essay, I have described some of the ways I prayed with my parents. I tried to illustrate that this activity of "praying with" has to be tailored to the style of spirituality and personal history of the person who is dying. Adult children need to follow the cues of attentiveness or disinterest of parents and must not impose their own piety on their parents or deny their parents spiritual comfort by not adapting to them. I also learned that I could not count on the local parish community to meet my parents' needs; although I still sought all the help I could get, because it is important to maintain the connection with the larger parish community.

Finally, it is important for adult children to get as much help as they can from the hospice team, which provides both a social worker and a chaplain. Although chaplains may not come from the same denomination or faith tradition, they are frequently more skilled in ministering to the dying than the average clergy person. The responsibility of caring for Alzheimer's-impaired parents is daunting on every level. I received considerable support from the hospice social worker and nurses, who helped educate and comfort family members who were less present to the process because of distance or other reasons. The neuropsychologist, who was part of a multidisciplinary team assessing elders at the University of California at Irvine, was consistently the most helpful in providing me with the neurological information needed for giving direction to our caregivers and in offering emotional support to me over a period of five years. This included in Mom's case especially how her brain was or was not functioning. So above all, adult children accompanying their parents need to rely on help from many sources, including both professionals and other spiritually oriented adult children who have journeyed with dementia-impaired parents.

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Losing Sight of Loss

Emilie Trautmann

"Health Hell" began for my husband, Jay, and me on a stunningly clear late spring day. Jay is an artist, and to supplement his income from the sale of paintings, he did development work for an artists' community. I am a freelance writer, and, at the time, both of us were working for the community. When Jay returned to our New York City apartment on that spring afternoon, I was sitting at a small table in our living room, trying to concentrate on the research in front of me despite the beauty of the sky cushioning a waning sun. I said hello to him and then launched into an explanation of the approach I was taking to the task before me. Undeterred by Jay's lack of response and somewhat blank look, I chattered away. Jay often engaged in what he called "space traveling." As far as I could tell, his space travels took his mind and spirit to unexplored realms that often appeared, in one form or another, in his paintings.

Growing tired of conducting a monologue, I demanded his opinion on the plan I had just outlined. He answered, "I had the sonogram today. They said I have a very enlarged liver and spleen." I wanted to know exactly what that meant. Immediately, I wanted to know who said what. All the details. But there were no details. A technician had delivered the news to Jay and had told him to call his doctor.

"So did you call Dr. Colbert?" I asked. Jay said no. I strongly suggested that he make the call instantly, which he proceeded to