



Mom's Alzheimer's and The Ethics of Letting Go

By SR. JEAN deBLOIS, CSJ, RN, PhD

I am a Sister of St. Joseph of Carondelet, an ethicist, a registered nurse — all of those things. And I am the daughter of a woman who, in 1982, died of Alzheimer's disease. Each of my roles has educated me, but the deepest, most far-reaching learning of all came from my mom.

THE DAUGHTER

It was about 4:30 a.m. on May 18, 1982. I heard someone knocking on my door. When I finally woke up and opened it, Sr. Mary Myles was there to tell me I had a phone call: "It's an emergency from the nursing home about your mother."

I took the call and learned my mom had suffered a seizure. I dressed as fast as I could and jumped in the car to drive the 24 miles from the convent in San Francisco to the nursing home in Lafayette, Calif.

When I got there, Mom was having continual seizures. The resident physician didn't seem to know what to do.

I am a registered nurse. "Give her IV Valium," I said, which the doctor immediately ordered, and the seizure activity calmed down. By the next morning, it was clear my mom had suffered what appeared to be a brain-stem stroke. Her body was flaccid; she was totally unresponsive to any kind of stimulation.

Progression through the stages of dementia robbed my mother of every human capacity she had.

For the next eight days, I stayed with her, talked to her, bathed her, sang to her and prayed with her. On about the fourth day of this vigil, Mom's doctor said, "We need to put in a feeding tube now." When I asked why, his response was, "So she won't starve to death."

I said, "No, Mom is dying, and I want to let her die in peace."

Over those last four days, I moistened her lips with water, turned her, bathed her and made sure she was comfortable. Mom died in my arms at 10 p.m. on May 25.

The journey through Alzheimer's to my mom's death started somewhere around 1977. Progression through the stages of dementia robbed my mother of every human capacity she had. It was a slow, painful process that she railed against, one I witnessed while experiencing a wide range of emotions from fear and anxiety to, at times, rage.

Mom was born on March 3, 1909. She met her future husband, my father, when they were in high school, and they married in 1935. They had a daughter in 1941, Dorothy Lee, who died when she was 3 years old, somewhere around the time that I was born in 1944. My parents never talked about their first daughter except to tell me she died very suddenly and unexpectedly from meningitis.

My mom was a very shy and private person, but she overcame that shyness because she was a very



involved mother. When I was in grammar school, she became the president of the Mother's Club. In 1952, she started a Brownie troop so I could be a Brownie and later became a Girl Scout leader so I could be a scout. She learned to do things like start a fire by rubbing two sticks together, weav-

At that time, Alzheimer's usually was only diagnosed at autopsy, but the internist said Alzheimer's "could be" what was going on.

ing lanyards, making baskets, getting certified by the Red Cross in lifesaving, all so the girls in her troop could get their merit badges in these and many other areas. She even braved the great outdoors to become a Girl Scout camp counselor.

Over the years, we talked about a lot of things, but never about what she felt. When I was going to nursing school from 1964 to 1967, I lived at the school but would come home on weekends. We had then what we would call today many "drive-way moments" where my mom and I would sit in the car after going shopping and just talk for 45 minutes to an hour about nothing at all.

I entered the Sisters of St. Joseph of Carondelet in 1968, much to the disappointment of both my mom and dad. I'm sure as their only child, they had hoped that I would marry and give them some grandchildren. But I had other plans.

I entered religious life in the days when we still weren't allowed to call home or receive phone calls. So when I got called to the phone at 7 o'clock on the evening of September 9, I was shocked to hear my mom's voice. She said "Honey, I have very bad news for you. Daddy died today."

I went home the next morning. I was there for his funeral, and I watched my mother try to grapple with the reality of life without him. About three days before I was scheduled to return to Los Angeles, where I lived and worked as a nurse, I sat down with Mom and told her that I would leave the convent, come home to be with her, live near her and work as a nurse in San Francisco. Without hesitation, she said, "No, you have your life, and that's what your father and I wanted for you ... just that you would be happy."

So I returned to Los Angeles and called my mom every Sunday. I tried to get home for a weekend visit whenever my work schedule would allow it, and I spent at least 10 days at home with

her every summer. For a few years, she seemed to be fine. She worked at *The Monitor*, the Catholic newspaper in San Francisco. She loved her job and the people with whom she worked. On August 1, 1975, she came to my final vows and told me then how happy she was that I was happy being a Sister of St. Joseph of Carondelet.

Over the next year, however, I started noticing changes in her. At first they were subtle. Long pauses when I spoke with her on the phone. Language that didn't make sense in the context of what we were talking about. And when I went home either for a weekend visit or during the summer, she would leave

the table in the middle of dinner and go and sit in the living room by herself. She appeared to be confused, forgetting where she was.

At first I thought she was suffering from mild depression. But as these symptoms and behavior changes worsened, I decided that we needed to see a doctor, something to which she was adamantly opposed. In those days, geriatrics was not yet the specialty it is today. Our only option was to see an internist who really didn't have much explanation for what was happening to my mom. At that time, Alzheimer's usually was only diagnosed at autopsy, but the internist said Alzheimer's "could be" what was going on.

Whatever the name was given to what was happening to my mom, it was clear to me that she was getting farther and farther away mentally, and she was becoming more physically challenged as well.

In 1978, my community gave me permission to resign my position at our hospital in Los Angeles and to study theology at the University of San Francisco. I thought I could live at our convent that was about three miles from my family home and keep tabs on Mom by visiting, doing her shopping, cooking and laundry. After about six months, I realized that she needed someone with her almost constantly. My community allowed me to move home, although I was still studying full time at USF. I found a wonderful woman, Marge, to come and stay with my mom during the day when I was in class, and it worked pretty well for the first few months. But then my mother became more and more angry and at times combative.

Her language skills were diminishing, and she couldn't carry on a conversation. But she could remember the words to every old song that I had grown up playing on the piano. So much of our time over the next year and a half was spent singing old songs that she seemed to love.



My mom had a brother and two sisters who lived in the East Bay area of San Francisco. While her brother was very attentive, her sisters seemed reluctant even to be around her. At first, I was angry about that, but I realized that Mom's behavior scared them.

Over the next several months, my mom became more and more confused. She would get up at all hours of the night, get dressed and go outside. She grew increasingly combative and also became incontinent. One day I had to leave for school before Marge got there. It was about 8:15 in the morning, but I knew Marge would be there no later than 8:30. I made the big mistake of leaving my mom alone.

I was in the middle of a class when a security guard from the school came into the room and asked where Sister Jean Katherine deBlois was. I raised my hand, and he asked me to come outside with him. He told me that I needed to go home because something had happened to my mother.

I raced home as fast as I could to find Marge standing on the front porch looking very distraught. It seems that shortly after I left for school, my mother left our house, still in her nightgown, with no shoes on, and walked eight blocks to our parish church to attend Mass.

My mother never attended Mass during the week that I ever knew of. She stayed for the whole liturgy, went to communion and walked home barefoot, by herself, and apparently none of the parishioners tried to help her. She somehow found her way back to our house, walked up the five steps to the porch and sat on the railing until one of our neighbors saw her and called the police.

That was the day I knew that I had to move my mom someplace else where she would be safe. I was fortunate to find a nursing home that was only five minutes away from her brother's home. The nurse in me resisted putting my mom in a nursing home, but the daughter in me realized that there was nothing else I could do.

We had a rocking chair in the living room of our family home that my mom sat in by the hour, looking out the front window. I brought her to that chair, sat her down and told her that I needed to talk with her about something important. I knelt down in front of her and said, "Momma, you are going to go live in a new home where people can take care of you and you'll be safe."

I'm pretty sure she understood what I was saying, because she grew very agitated and angry. I can remember that scene to this day.

About a week later I took her to the nursing home. Her brother and sisters did not offer to come with me, so I did it by myself. We sat in the car for a long time. She had not spoken a whole sentence in almost two years, but that day she kept saying, "Let's go home now. Let's go home now. Let's go home now."

I finally mustered up the courage to take her into the nursing home and introduce her to the staff. I got her settled into her room and stayed with her for few hours. As I was getting ready to leave, Mom didn't seem to notice.

I sat in the car in the parking lot of the nursing home and sobbed. I thought my heart was going to break. That was the hardest thing I've ever done in my life. In retrospect, I know that I had no other choice, but I still feel like I abandoned my mother.

I went to see her at least two times a week, and every Sunday took her to my uncle's for dinner. But from the day she went to the nursing home, Mom grew farther and farther away. One day about six months later, when I went to visit with her, it was apparent to me that she did not know who I was. That was sometime in late 1979.

In retrospect, I know that I had no other choice, but I still feel like I abandoned my mother.

During my final year of study at USF, my community encouraged me to consider getting a doctorate in moral theology and medical ethics so I could teach at our college in Los Angeles where we have a baccalaureate program in nursing. I was quite reluctant to consider this, because the only university offering such a degree at that time was the Catholic University of America in Washington, D.C. I could not imagine being that far away, but my uncle encouraged me to do it, promising that he would visit Mom every day and keep me posted on how she was doing. After long hours of prayer and lots of tears, I applied to Catholic U. and was accepted.

Saying good-bye to my mom in August 1980 was the second hardest thing I have ever done. I called her every Sunday and sang to her over the phone, told corny jokes and told her about what I was doing. The staff at the nursing home would hold the phone to her ear, but she never said anything in response. I went home at Christmas and in the summers. I had just returned home in mid-May 1982 when Mom died.

THE NURSE

I graduated from St. Joseph College of Nursing in 1967 and received my RN the same year. I worked for a year at the hospital where I trained. I entered the Sisters of St. Joseph of Carondelet in 1968 and worked at Daniel Freeman Hospital in Inglewood, Calif., for the next eight years as a critical care nurse and a paramedic base station coordinator.

The people I cared for were mostly the victims of heart attacks, and in those days were pretty young, in their 40s or 50s. Once they were over the acute phase of their illness, they felt and appeared to be well. So my 10 years of nursing experience did not prepare me for what happened to my mother. I had no idea how to deal with the increasing confusion and anger that she displayed.

I also wasn't prepared for the kinds of emotions I was experiencing. I am pretty much a "left brain" kind of person, and, working in critical care, I learned to suppress feelings. When I found myself unable to do that, it scared me. I am also a

To a person, they say they are so grateful to know that they can stop life-prolonging treatment when it is clear that it will not contribute to the kind of life their loved one wanted.

very private person, and I didn't share what I was feeling with anyone.

I told myself again and again, "You're a registered nurse. You can handle this." I could not have been more wrong. I second-guessed every decision I made about Mom's care. I felt totally inadequate to bring up to the nursing home staff issues that I thought needed attention. In retrospect, I don't understand why I felt that way — and I carry around a good deal of guilt about that.

The only time my nursing experience kicked in was during the final eight days of my mom's life:

I dismissed the physician who wanted to put in a feeding tube.

I asked that mom's roommate be moved to another room so we could make her final journey together, without anyone else present.

I let her brother and sisters know that Mom was dying and that if they wanted to see her one last time, they should come soon. They never did.

I completely took over her physical care, and know I took excellent care of her. It is this real-

ization that has allowed me to forgive myself for not being there for her on so many occasions, although, even after all this time, I still struggle with that guilt.

THE ETHICIST

I was just at the beginning of my doctoral studies when my mom died. Ethics as a discipline was just beginning to be recognized as important in medicine and health care. I graduated from Catholic University in 1987 with a doctorate in moral theology and medical ethics. Since that time, I have taught ethics, served as an ethics consultant and done hundreds of ethics consultations, most of them on issues at the end of life. I have worked with many, many family members of persons with advancing dementia, especially on the issue of artificial nutrition and hydration.

I think it was my experience with my mom that taught me more about this issue than my formal ethics education did. When Mom's doctor said,

"We have to put in a feeding tube ... so she won't starve to death," my first question was, "What good would that do her?" That is the question I tell family members they should ask about their loved ones who are in advanced dementia when any kind of life-sustaining intervention is suggested by physicians, clergy and others: "What good would that do for my mom, my dad, my husband?"

My mom's life could have been prolonged, but the life that was meaningful to her was extinguished on the day she no longer knew her daughter. This is the experience of so many people whose loved ones suffer with Alzheimer's and other forms of advancing dementia. There have been so many people who have come up to me with tears in their eyes after I have given a talk on the use/non-use of life-sustaining interventions in persons with Alzheimer's or other chronically debilitating illnesses. To a person, they say they are so grateful to know that they can stop life-prolonging treatment when it is clear that it will not contribute to the kind of life their loved one wanted.

Over the years, I have learned that "doing ethics" is not simply about following rules, whether they are established by the church or some other form of authority in our lives. Ethics is fundamentally about helping persons, in the context of the various communities of which they are a part,



understand how to live well and pursue the purposes of human life in ways that are meaningful and fulfilling for them.

We all strive after meaning in our lives in light of our specific needs, gifts, limitations and circumstances. While life's purposes are pursued in our jobs and profession as well as in creative activities and the like, they are most basically pursued through the development of relationships. As persons experience the gradual diminishment that life brings through illness, injury or aging, pursuing the purposes of life, that is, finding meaning in one's life, can become increasingly challenging.

The support of community — family and

friends, caregivers — is critical. And it often falls to family and friends to make the decision that the ability to find meaning and fulfillment in life is no longer possible, given a loved one's condition, or, if it is possible to some extent, it involves too much burden. I made this decision for my mother, and I pray for all those who have to struggle with similar decisions.

My best teacher in all of this was my mom.

SR. JEAN deBLOIS, CSJ, is professor of moral theology and director of the Master of Arts in Health Care Mission program at Aquinas Institute of Theology, St. Louis.

Educational Events

from The Catholic Health Association

2014

International Outreach Webinar:
Sharing Results — CHA Short-
Term Medical Mission Tips
Phase 1 Research Findings
Nov. 13 | 2-2:45 p.m. ET

Foundations of Catholic Health
Care Leadership — An Online
Course for Formation and
Development

Six consecutive Fridays
Feb. 13 - March 20 | 1-3 p.m. ET

Theology and Ethics Colloquium

March 25 - 27 | INVITATION ONLY

Catholic Health Assembly

June 7 - 9

**Note: Program dates and locations
subject to change.*

2015

System Mission Leadership
Forum
Feb. 3 - 5 | INVITATION ONLY

Ecclesiology and Spiritual
Renewal Program for Health
Care Leaders

April 19 -24 | INVITATION ONLY



Catholic Health Association of the United States
A Passionate Voice for Compassionate Care®

chausa.org/calendar

JOURNAL OF THE CATHOLIC HEALTH ASSOCIATION OF THE UNITED STATES

www.chausa.org

HEALTH PROGRESS®

Reprinted from *Health Progress*, November-December 2014
Copyright © 2014 by The Catholic Health Association of the United States
