

“Families Are Also Victims of Alzheimer’s Disease”

At one time or another most of us have known or heard of someone who suffers from a chronic disease, illness, or condition. Whether the victim is a family member or just a close friend, the experience can be disruptive, heartbreaking, and emotionally draining, and the very presence of the disease or condition taxes the nerves, patience, and resources of both its victims and their families. A few years ago such a crisis affected my own family when my father was diagnosed with dementia, and the following is a recount of my family’s experiences when my father was diagnosed with Alzheimer’s disease (AD) at age 85.

It was especially difficult for my brother and me, as his sons, to witness the mental, physical, and spiritual decline of someone who had always been so sharp and alert, so strong and decisive, and so intelligent and well-read. Our dad was self-taught and extremely talented; he was capable in a wide and diverse range of areas. He could accomplish nearly anything he decided to do with very little—if any—guidance. He enjoyed playing chess and, for those who are familiar with tournaments, his skill probably was something on the order of “Master” level. He was a prolific writer; he painted and played the piano and organ; and he was a fantastic cook. However, what he enjoyed most as he entered middle age was flying small aircraft. After he earned his private pilot’s license at the tender age of 56 he flew nearly every weekend until high blood pressure and deteriorating eyesight prevented him from passing the required F.A.A. physical exam and therefore from renewing his pilot’s license. Although obviously depressed by this unexpected and devastating “handicap”, he continued pursuing his other interests. Unfortunately, after this dreadful disease developed into the latter stages he remembered doing none of those things. All of his accomplishments were lost, except to the extent that they still remained as cherished memories for members of his family.

As with so many others afflicted with early-stage AD, his initial symptoms occurred infrequently and were not always obvious. In 1997 he had suffered from a series of strokes that left him with slightly slurred speech and motor dysfunction, both of which improved over time through a combination of physical therapy and his body’s own natural healing powers. The slight occasional lapses in memory and recognition that followed initially were attributed to these strokes, but were later diagnosed as an early stage of dementia. The behavior they induced was in sharp contrast to what was normal for someone who previously had always been alert and mentally extremely sharp.

The symptoms of AD can vary greatly from one victim to another, but generally include memory and recognition loss, delusions, obsession or “fixation”, disorientation, reduced attention span, and, eventually, a nearly complete loss of the sense of time. In the early stages there are “good” days, during which the victim appears nearly normal, as well as “bad” days, during which symptoms of the disease are very apparent. Nearly all who are afflicted and who survive long enough for this disease to run its full course inevitably deteriorate—both mentally and physically—to the extent that it is no longer appropriate or safe for them to continue living with their loved ones in a normal residential environment. It was this prospect that my brother and I dreaded the most and probably subconsciously refused to accept. Although it eventually becomes necessary for a caregiver to make the decision to place the victim into a facility where he or she can receive the type and quality of medical care and monitoring that cannot be administered at home in a convenient and practical manner, the decision is still painful and heartbreaking.

In one way or another Alzheimer’s disease touches all who come into contact with its victims, but especially family members. Many of the episodes my father experienced were so severe and disturbing that they left lasting impressions for my brother and me. A revealing and touching example of this is an incident that occurred in our household in early November of 2001, and the images of that event probably will remain indelibly etched into my memory for as long as I live. My brother and I were abruptly awakened at approximately three o’clock in the morning by my father’s agonizing cries. He was desperately trying to convince us to escape from what he imagined to be a fire that was raging in the house. We probably will never know exactly what triggered this delusion, but my guess is that the combination of crackling sounds from the television the previous night, coupled with what must have been for him a vivid, disturbing dream, served as the basis for his imagination to conjure a scenario in which sparks in the electrical wiring behind the walls caused a fire in the house during the night. I shall never forget the image of my brother and me sitting on the bed on each side of our agitated, wild-eyed father as we attempted to physically restrain him from running nearly naked out into the frigid late fall night. Even worse, we were rewarded for all of our concern, effort, and lack of sleep by being subjected to vicious accusations that his two sons were trying to kill him by forcibly trapping him in a house that he was convinced was about to become a blazing inferno! Even after my father calmed down many hours later, he still insisted upon having heard fire trucks responding to this imagined conflagration. As the day progressed, however, he began to relax and eventually forgot about the incident entirely, never again referring to the matter as long as he lived, and the events of that night were never repeated.

One of the few physicians who cared for my dad over the years informed me that a rather bizarre symptom that is common to nearly all Alzheimer’s victims is what he called “freezing,” which manifests itself as a waking, trance-like state in which the

victim appears to suspend his thoughts and physical activities literally in mid-stream, and then to resume them again afterward. For my dad these episodes would last anywhere from a few minutes to many hours, and appeared to occur with increasing frequency over time. When they began he might be struggling to concentrate on a problem or to reflect upon a real or imagined situation. While in this condition my father seemed to have forgotten what he had been doing and thinking about just seconds before its onset, and afterward appeared to be completely unaware of having experienced it at all.

The reduced attention span and concentration that caused these “freezing” episodes also caused my dad to forget to complete even the simplest of the daily tasks which he started. One night my brother got up during the night to find one of the kitchen gas range burners left on! Apparently, my dad used it to heat something and simply walked away without shutting it off. We were fortunate not to have had a genuine blazing inferno that night! The following day my brother discontinued gas service to the house.

My father also often forgot to turn off the kitchen or bathroom faucet after washing his hands or brushing his teeth. On one occasion he decided to stop up the bathroom sink drain while running the faucet, creating a flood after the sink basin filled up. In order to avoid a repetition of this incident, we actually had to reduce the faucet water flow rate to a bare trickle.

As his principle caregivers, my brother and I desperately wanted to avoid placing my father into a nursing home, having committed ourselves to caring for him at home. I would like to believe that I personally harbor no preconceived prejudice against nursing homes, assisted living facilities, or similar facilities for housing and care of the elderly. Despite occasionally seeing or hearing news reports concerning abuses or neglect that occur in such places, I am still convinced that most of them generally are very fine institutions, each with dedicated and competent employees, even if they often are understaffed. They obviously fulfill important medical and social needs and are essential when families truly are unable to care for elderly relatives themselves. However, my brother and I were still not entirely convinced that in one of these places our father could possibly receive the personal attention, patience, understanding, and overall quality of care that only a loving family can provide in a friendly and familiar home setting. Accordingly, our plan was to keep him at home with us for as long as possible. Unfortunately, however, this plan proved to be both shortsighted and short lived when I finally was faced with making this dreadful decision approximately six months later.

In May of 2003 I had decided to personally accept the job of caring for my father by taking him with me to live with my oldest daughter, and within another two months we all moved down to Florida. Previously, my brother and I shared this responsibility. My dad’s condition had been deteriorating steadily, and his psychotic episodes were more frequent and becoming more pronounced.

One of the most widely publicized issues surrounding Alzheimer’s disease—and perhaps one of the most distressing for immediate family members—is that of memory loss, including the victim’s increasing lack of recognition of familiar individuals. I dreaded the day when this horrible affliction would transform my father into a virtual stranger in our midst. When we moved to Florida his recognition already was becoming infrequent, and I feared that the days of having any meaningful communication with him were numbered. Watching someone’s brain literally die before your eyes is heartbreaking, even more so when the victim is a loved one and, especially when the victim was as active and engaged in life as my dad was.

During the course of the five or six months that we lived in our Clearwater, Florida apartment my dad’s behavior became so unpredictable and unmanageable that he began to pose a serious risk to himself and to others in our household, especially to my then-four-year-old grandson. Because of his deteriorating health, as well as for his own safety and for our overall peace of mind and sanity, my daughter and I decided that the best place for him was in a facility that could offer him 24-7 care and the increasing medical attention he would need.

At the time of his admission to the nursing home in Florida my father already was experiencing what is referred to as moderately severe-to-severe cognitive decline. He exhibited all of the listed symptoms as I understood them, but to varying degrees. However, during the nearly seven months he was there until his death his decline continued. Near the end he appeared nearly catatonic most of the time, although there were occasional eruptions of sporadic, though indiscernible, verbal activity. During our last few visits he no longer appeared to recognize me or my daughter and barely even acknowledged that we were there. Because his fear of falling had become an obsession, he was completely unwilling to get out of the wheelchair to walk, despite the best efforts of the staff to encourage him to do so. This resulted in leg and foot muscle atrophy and loss of tissue mass. His rate of general mental decline appeared to be accelerating, and even some autonomic nervous system responses appeared to be failing—an inevitable condition that we had been warned to expect shortly after he arrived. Indeed, it was a heartbreaking picture, one that I certainly would not treasure among my final memories of him. In fact, I could not bring myself to take a camera with me whenever I visited him at the nursing home. It would be painful enough for me to have to carry those mental images with me for the rest of my life without having actual photographs to document them, as well. It is not the way I would want to remember him; it is not the way I would want my kids or grandkids to remember him, and I was also sure that it is not the way he would want to be remembered by anyone.

My father passed away on Friday November 6th, 2004 after living at the facility for about seven months. Four days earlier I had moved back to Long Island to live with my brother and mom. Early in the morning of the following Sunday—two days after receiving the call from the nursing home—I was on my way in the car back down to Florida to make the arrangements for his final resting place. The official cause of death was respiratory distress and massive renal and circulatory failure. The disease that for so many years had devastated his mind finally laid waste to the rest of his body and conspired with the normal ravages of time and age to completely finish him off.

It is a well documented fact that the grieving process varies greatly from one individual to the next. Curiously, when my father passed away I didn't shed even a single tear; I did not experience the kind of loss and grief usually associated with the death of a parent. I certainly missed him and I felt much poorer for his loss, but more as a close friend or well-known public figure that I admired than as the father whom I had known, loved, and revered all of my life. Perhaps I didn't experience the depth of loss and grief that I expected to feel because in a very real sense the man whom I knew as my father had "passed away" years earlier. He had disappeared and had been replaced by another person—in fact by many persons—and I had begun to miss the dad I knew even back then. Also, I could not experience the customary relief for the end of his suffering from this disease, in keeping with the old cliché. In hindsight I suspect that this was because, being completely unaware that he had any affliction at all, he really didn't appear to suffer. In his absolute confusion, he did not even realize that he was confused, or if he was confused, he soon would not recall being confused. In his total disorientation he didn't even realize that he was disoriented. Because of his severe memory loss he didn't recall forgetting anything. He was blissfully unaware of any abnormality or of just how much he had lost mentally. While he was still alive it was we, his children, who suffered because we were painfully aware of everything that he had lost and, accordingly, of what we had lost, as well. Fortunately for him, the worst suffering probably occurred only near the very end as his body approached the final stages of shutting down. I can only hope that this suffering was very brief.

Although my father is gone, I know that somehow he is never very far away. He is still telling his off-color jokes, plying a new strategy in some cosmic chess game, baking another mouthwatering Sicilian pizza and, of course, flying his Cessna 152 in an endless, eternal, blue, and windless sky. Wherever he is and whatever he's doing, I hope he is happy and I know that he's watching over me and patiently waiting for me to see him again. God willing, some day I shall.

I would like to offer a few final pieces of advice to those families who have loved ones who currently suffer from some form of dementia, and who currently reside in nursing homes, as my father once did: **PLEASE DO NOT ABANDON OR GIVE UP ON YOUR LOVED ONES.** Just because they don't appear to recognize you or sometimes don't seem to acknowledge your presence when you visit, don't automatically assume that they can't somehow sense that you are there and can't feel the love and support that you evince when you come to see them. Believe me; your visits and your attention are far more important to them than you might think. I am convinced that my dad somehow sensed it when I visited him, even long after he could no longer meaningfully articulate or display his feelings. While you still can, talk to your afflicted loved ones and don't be afraid to show affection, even if it doesn't appear to be reciprocated. You should never feel foolish or ashamed to continue trying to communicate, even if it appears hopeless or useless. They might feel a little better for it, and you definitely will, not only during your visit, but also after they are gone because you'll know that you made every effort to see them, to communicate, and to display your love and affection at a time when they needed it most.

Finally, after they have passed, cherish the memories of your afflicted loved ones, especially their moments of love and personal triumph. Do not mourn their loss. Rather, celebrate their lives, what they meant to you, and how much better you are because you were privileged to know them. May all of your memories be pleasant ones. I offer my best wishes and prayers to all of you.

Robert Marma
—in loving memory and recognition of, and honor for my dear departed father, Emil Marma