
Amid the Flood

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The years of our life are threescore and ten,
or even by reason of strength fourscore;
yet their span is but toil and trouble;
they are soon gone, and we fly away. . .
So teach us to number our days
that we may get a heart of wisdom.

Psalm 90:10, 12 (RSV)

When he died in 1989, the sum of Dad's years came closer to fourscore than to threescore and ten. With the psalmist, I attribute this number to his strength, but I would not wish the manner of his death on anyone. He died of complications due to Alzheimer's disease.

It was my first experience with the death of an immediate family member, so I was no veteran. I found myself up against a more complicated reality than I had anticipated. I remember thinking at the time that some portion of this is just plain death: nasty, sad, the way death always is. But it is not natural death. It is something else. In the words of Martin Luther's signature hymn, the disease threw every member of Dad's little nuclear family—his wife, daughter-in-law, and myself—into a "flood of mortal ills prevailing."

I

Let us be clear about some things. During the period of his disease, my father did not live with me. Since I was never his "caregiver," I was never burdened with his day-to-day care as a victim of Alzheimer's disease. To be sure, I certainly needed help during this period. But it is the caregiver, usually the spouse of the victim, who needs help the most. In fact, if my experience is any measure, caregivers often need more help than the victims. Most often, the type of help they need is companionship. As is the case with other diseases that involve substantial pain or deterioration, the funeral comes as something of a relief for the living. The chief difficulty turns out not to be death itself, but coping with the disease in its early, middle, and late stages. *That* is when the caregiver is likely to be quite alone.

There are a number of ways to describe what a close relative or caregiver for an Alzheimer's victim goes through. There is the *shock* of discovering that a loved one has the disease, there is the *sadness* of watching someone unravel mentally before your eyes, and there is the *test* of coping daily with an Alzheimer's victim. Some call it an endless funeral. I have another term. What

we are coping with is *death empowered*. The Apostle Paul called death "the last enemy" (1 Cor. 15:26), as if death were an aggressive force, a spiritual power with a kind of agency. It is. You see it in warfare, in AIDS that threatens to become a plague in Africa and Southeast Asia, and you see it in the homes of Alzheimer's victims. Death "gets up on its feet," so to speak, and starts throwing its weight around. Not many things can resist the power of death. Christ can, but even for him, the Apostle Paul said, death was the *last* enemy. Before it kills the things that we can see, death kills things we cannot see. It attacks our souls, our lives, our confidence, and our vitality. If you doubt that, look at the eyes of the people who spend long hours in the presence of Alzheimer's disease.

Before Alzheimer's struck Dad, I wish someone had talked to me about Psalm 90, and the wisdom of numbering our days. The point was driven home to me when Bill Moyers produced and directed, "On Our Own Terms. Moyers on Dying"—a four-part series shown during September, 2000, on most PBS television stations. By any measure, it was riveting television. Moyers's target was not the moment of death, but the part of the dying process that multiple surveys report Americans fear most: *the terminal phase*, the four to six months prior to the moment of death. He focused his cameras on our fear of dying and on the denial of death in our culture. *Can we learn to live with dying?* was the question.

Moyers explored the emergence of "palliative care," an approach that stresses pain management and a more holistic focus on dying patients' emotional, physical, and spiritual wellbeing. The series was full of inspiring stories of nurses, physicians, hospice volunteers, poets, patients, and in particular families and spouses, who bear witness to their love by giving sufferers dignified, consistent care and companionship. One pair of reviewers was so impressed by this that they suggested the episode might well be used with couples preparing for marriage!¹ Although I support their suggestion, I also know that modern Christian communities have a titanic job ahead of them in this connection. Perhaps the greatest temptation among Christian laypeople today is to push their pastors toward the dying in order to compensate for their own distance from them. They leave it to the clergy to assist bereaved families while they themselves avoid funerals unless they have some clear social obligation that forces them to attend. Although they may not have been surprised, Christians may still have been struck by how infrequently the church appeared in Moyers's series.

But before we are able to mourn with those who mourn, most of us will have to relearn the ancient religious practice of *living with dying*—our own dying as well as that of others. Psalm 90 appears to assume that numbering our days is a practice everyone needs to be *taught*. It clearly implies that death is too important an event to be left to doctors and clergy. As a prophetic professor at Yale University puts it, "Death is not a medical event. It is a personal event. Death is not owned by doctors. Death is owned by the dying."²

The so-called "medicalization" of death is a reality for most Americans. Though many of us say that we want to die at home with friends and loved ones nearby, and to have a measure of control at the end, it is doubtful that most of us will actually end our days that way. The manner in which we are likely to die has changed dramatically over the last half-century. Physicians, HMOs, and old-fashioned greed share part of the responsibility for the dark side of this change, but only with the collusion of their patients and clients. It is difficult to avoid the conclusion that *we* (the patients and clients) deny death, that *we* distance ourselves from death, and that *we* are often quite happy to let the doctors handle it. A terminal patient on the Moyers's series says, "Practically all my friends have stopped coming to see me. But I don't blame them. I remind them of their mortality."³

Alzheimer's disease is a serious and irreversible form of dementia. It has no known cure. Its typical pattern with respect to memory is to plunge victims into a near-terminal phase "early" and to hold them there for years. It is a peculiarly potent form of being-toward-death⁴ to which the church needs to construct a considered and humane response.

II

In my father's case, it became fashionable to say, "Nothing really helps." In fact, however, there were many things that helped. Even when he could not follow the Scripture lessons nor read the words of hymns, to be present at worship services lifted him. Worship is so much more than *thinking*. The songs, the colors, the music, the movement, the pageantry, and the warmth of other people may well communicate something to a person who can no longer read a single line in the church bulletin. Our family also found that Dad's prayers before meals remained clear, even rather late in the disease's progression. If victims of Alzheimer's disease have prayed in the past, they are helped by continued opportunities to pray in the present.

People are different. Being at worship services *always* lifted my father. If he had been a different kind of person, his spiritual support system would have had to take a different form to be effective. But every Alzheimer's victim (and every caregiver) has a need that is spiritual. The terrible, death-dealing dimension of Alzheimer's disease resides in its power to destroy hope. It breeds cynicism and despair, not only about the victim's life, but about life itself. We plan carefully for retirement, we enter it with a nest egg, a healthy spouse, and wonderful plans, and then . . .

Alzheimer's disease can devastate the family structure—financially, psychologically, emotionally, and spiritually. The family is a sacred place where new life is nurtured, where we discover we are loved, where we first learn to stem self-interest for the sake of others, where we gain hope and confidence in a higher power. Alzheimer's takes aim at all these blessings. Soon after my father was diagnosed as an Alzheimer's victim, my mother began referring to the disease as the "monster." Now that Alzheimer's disease is on the church's

agenda, I have three suggestions for caregivers and friends who have to cope with this monster.

Prepare for a spiritual struggle.

Among the number of things I learned from my experience, this is the main one. No matter how courageously your spouse or parent deals with the disease internally, no matter how supportive your friends are, "death" will begin to push you around. Death has two faces. One is an event at the end of life, and the other is an active power, a force.

The victims of Alzheimer's disease and their caregivers need a hope that death cannot destroy. They need room to question God, because the disease raises the most ancient and profound question about divine goodness: "Why me, Lord?" They need a perspective on suffering in order not to be pulled down into self-pity. They need spiritual strength. In this struggle, Scripture must not be overlooked. The Psalms are helpful both because of their beauty and depth, and because of the honesty and vigor of the psalmist's complaints against God. The Book of Job is a classic on the problem of suffering. The sixth chapter of Ephesians is a powerful statement on the way faith can be a shield and protection against death's power. The fifteenth chapter of First Corinthians, Paul's best-known statement on the resurrection, can be of great help and comfort.

Do not try to be a Lone Ranger.

The burden of coping with a loved one with Alzheimer's disease is simply too heavy and too complicated to be borne alone. Rely on friends, relatives, neighbors, support groups, and local congregations. Accept their variety of gifts—as cooks, as nurses, as people with helpful contacts, as friends with whom the victim is at ease. Again, I cannot overemphasize that because Alzheimer's disease is a vehicle for death-as-power without the accompaniment of death-as-event, the family of a victim is thrown into a grim and mournful process.

Both the Alzheimer's victim and the caregivers increasingly need all kinds of support over the course of the disease. In my father's case, a schedule was worked out with retirees from his church, whom my mother called "angels." Every week, two or three of them took Dad for a ride downtown or out in the country. This had always been one of his favorite activities. What made these men truly angelic was that they gave *both* my parents what they needed—a ride for my father and respite for my mother.

Alzheimer's support groups are located in or near almost every community. Our experience reminded us that because people are different, they may respond differently to such opportunities. My mother did not find support groups helpful, but the resources they provided proved to be of genuine assistance to my wife and me.

Remember that you are a source of wisdom to others.

Friends, social agencies, churches, and even doctors need the help of caregivers. People tend to be leery of Alzheimer's victims. They are afraid of being embarrassed, and they frequently do not know what to do. Often this fear and anxiety extend to the caregivers themselves. In social situations, should they mention the disease? If so, what should they say? Such uncertainties may well result in keeping silent.

Most people find it difficult to "read" Alzheimer's disease. They need the caregiver to inform them about its impact on the victim, on the family, and on everyone's natural support system. The task of interpretation is particularly critical in the disease's early stages, and the caregiver is in the best position to do it.

The two best institutional responses to this crippling illness are (1) the Alzheimer's Disease and Related Disorders Association, a national organization working to support caregivers across the country and to stamp out the disease, and (2) churches that are beginning to shape sensitive and effective responses to it through Stephen's Ministry initiatives, Deacons' Care Networks, and the more spontaneous activities of "angels." Because of the spiritual challenge often hidden within the illness and because of its impact on family systems, the church's response is especially important.

Christ taught that we should have no trouble knowing where to find him. He will be among the "least of these" (Matt. 25:40, 45). More often than not, what Alzheimer's victims and their families need is a kind word, a part of an afternoon, or perhaps a few dollars. Such simple acts speak to a crying need in the lives of people trying to cope with the monster named Alzheimer's.

ENDNOTES

¹ Keith G. Meador and L. Gregory Jones, "Bearing Witness in Life and Death," *Christian Century* (August 16-23, 2000), 803.

² See Sherwin B. Nuland, *How We Die: Reflections on Life's Final Chapter* (New York: Alfred A. Knopf, 1994).

³ For a rigorous assessment of modern death denial, an assessment which points toward but does not embrace Christianity, see Ernest Becker, *The Denial of Death* (New York: Free Press, 1973).

⁴ The roots of the term may be of interest. In Martin Heidegger's major work, *Being and Time*, trans. Macquarrie and Robinson (New York: Harper and Row, 1962), the philosopher so classifies *all* human beings. Heidegger's thesis appears dependent on a Leo Tolstoi short story, "The Death of Ivan Ilyich" (1886), the subject of which was the inauthenticity of any human life that has not learned to live with death. The story is one of *Six Short Masterpieces by Tolstoi*, trans. Wettlin (New York: Dell, 1963), 221-83.