

The Human Face of Alzheimer's

Colleen Carroll Campbell

When Ronald Reagan slipped the surly bonds in June after a long battle with Alzheimer's disease, Americans seemed to grieve his manner of dying as much as his death itself. Stories abounded about the indignities that Reagan had suffered in his last years, including his inability to recall his two-term presidency and his failure to recognize Nancy, his wife of 52 years. A decade after Reagan had announced his Alzheimer's diagnosis in a letter to the American people, he once again brought the horrors of this progressive, degenerative brain disease into the national spotlight.

From coast to coast, pundits repeated the conventional wisdom that Alzheimer's had rendered Reagan a mere shadow of his former self. *Chicago Sun-Times* columnist Richard Roeper said the former president had been "alive in body, but his spirit was gone." *Boston Globe* syndicated columnist Ellen Goodman said Reagan had suffered from a "disease that kills the self." In the *Minneapolis Star-Tribune*, Doug Grow argued that a day of celebration would have been more appropriate than a day of mourning: "[H]ow can there be tears after seeing a person lose everything from memory to dignity?" Law professor Paul Campos wrote in the *Rocky Mountain News* that Reagan died "a horrible and depressing death.... [W]ould it not have been better for everyone, not least of all Ronald Reagan himself, if he had died of a heart attack several years ago?" An anonymous reader writing to the *Seattle Times* seemed to think so. "Thinking about (Reagan) and others living ten years with the disease is appalling. If I were ever diagnosed with dementia, I'd want to investigate suicide. Does one need to move to Oregon?"

The public consensus on Reagan's death was immediate and reflexive: His physical passing was a mere formality, the symbolic loss of a man who had vanished long ago. Nancy herself seemed to indicate as much at a fundraiser she attended weeks before her husband's death. She told the audience, "Ronnie's long journey has finally taken him to a distant place where I can no longer reach him." In one sense at least, Reagan's widow had lost her husband long before pneumonia took his life on that June afternoon.

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And yet, another view emerged in the wake of Reagan's death, a perspective framed by photojournalists on the scene at the former president's funeral. In the images they captured, Nancy's grief over her husband's death appears intense, even overwhelming. One picture finds Nancy flanked by her children, her head resting lightly on the chest of her son, Ron. She is small and frail, standing barely taller than the elevated casket in front of her. She grips a carefully folded American flag in her left hand and covers her eyes with her right. Her face is clenched in the contorted half smile of one trying to restrain her grief. Nancy is weeping, and she seems to be reeling from an unexpected blow.

The photo, taken as Nancy bid farewell to her husband's body, quietly defies the notion that Reagan's death was anticlimactic. Debilitated as he was, Reagan's physical presence clearly mattered to Nancy, and friends say his death hit her hard. Daughter Patti Davis described Nancy's shock and sorrow in a *People* magazine essay: "My mother is tiny, her weight against me light.... But her grief is huge and so heavy it pulls on the joints of my body. It will be okay, I tell her, but I have no idea if it will be."

Nancy's profound sense of loss echoes what many Alzheimer's caregivers feel when death finally arrives for their loved ones. Given our culture's conventional wisdom about the severely demented—that their lives are "not worth living" or that they are "not living at all"—the intensity of grief often catches caregivers off guard. Terri Jo Barron, a Florida woman interviewed after Reagan's death, summed up the experience of many when she told a *USA Today* reporter about losing her husband after an eight-year battle with Alzheimer's. "I really thought because I had been anticipatory grieving for years that the actual loss would not be hard," Barron said. "And I was wrong."

The loss is hard because, beneath our modern, dualistic tendency to value mind over matter, we still believe the body counts. And despite our culture's insistence that the human person is defined by rationality and autonomy, we have an inchoate sense that the truth is more complicated than that. The tension between our public rhetoric and our private experience, between our reverence for reason and our attraction to the mysteries beyond its reach, simmers just below the surface of our national conversations about science, healthcare, and aging. We usually succeed in keeping that tension under wraps, and keeping our focus on how modern medicine and biotechnology can help us avoid disease and death. But every once in a while, we face a situation that forces us to collectively consider what it means to be human persons who grow old, suffer, and die.

The looming Alzheimer's epidemic is just such a situation. This disease embodies everything we fear most about aging—weakness and dependence, humiliation and oblivion. Its insidious onset and relentless progression have penetrated our collective consciousness, and nearly half of Americans over the age of 35 know someone personally whose brain has been ravaged by it. As Americans are living longer and more physicians are recognizing dementia as a disease to be diagnosed, Alzheimer's is claiming more victims. Some 4.5 million Americans suffer from Alzheimer's today, more than double the number who had the disease in 1980. Alzheimer's has become the eighth-leading cause of death in America, and its impact is expected to mushroom as 77 million Baby Boomers head into retirement. By 2050, if no cure is found, 16 million Americans could have Alzheimer's. As they bid their long goodbye—Alzheimer's can take up to 20 years to run its devastating course—we will no longer be able to ignore the human questions raised by this disease. Such questions, about the basis of our human dignity and our identity as persons, cannot be answered by science or technology. We must grapple with them the old-fashioned way, drawing on both reflection and lived experience to find the meaning in this way of dying.

The Disease of the Century

The late medical essayist, Lewis Thomas, famously labeled Alzheimer's "the Disease of the Century." Thomas explained its significance in a 1992 essay: "Of all the things that can go wrong in aging, the loss of the mind is far and away the worst and most feared. And here, I believe, is the greatest of all opportunities for medical science in the improvement of the human condition."

Medical science has tackled the task with vigor. Since 1906, when German neuropathologist Alois Alzheimer first described the abnormal clumps and tangled bundles of fibers that he found in the brain of a deceased dementia patient, scientists have slowly unraveled the secrets of this disease. The amyloid plaques and neurofibrillary tangles identified nearly a century ago have become known as the hallmarks of Alzheimer's, which causes the gradual loss of brain cells in its victims, and leads to memory loss, disorientation, hallucinations, and death.

Alzheimer's researchers still do not know what causes the disease, or how to cure it, prevent it, or stop its progression. But they are making strides on all fronts and their ranks are growing. In his recent testimony to a Senate subcommittee on aging, Johns Hopkins psychiatrist Dr. Peter

Rabins reflected on the shift he had witnessed in the past 30 years: “I have watched Alzheimer disease change from a condition known to a handful of experts to a disorder that is feared universally.”

No longer the province of a handful of pioneers, Alzheimer’s research is now a booming enterprise. The ninth annual meeting of the International Conference on Alzheimer’s Disease and Related Disorders in Philadelphia was a good example of the change. Some 4,500 researchers attended the conference in late July 2004, sharing findings from 2,000 studies that showcased the latest advances in Alzheimer’s treatment and prevention. Highlights included revived hopes for a vaccine that could mobilize the body’s own antibodies to fight Alzheimer’s; reports detailing recent advances in brain imaging technologies such as PET and MRI that allow earlier diagnosis; and evidence that the drug donepezil, trademarked Aricept, can delay the onset of Alzheimer’s by about six months in people with mild cognitive impairment.

Research into the environmental and genetic factors contributing to Alzheimer’s also has made headlines. At the Philadelphia conference, scientists unveiled studies suggesting that what’s good for your heart may also be good for your brain. By exercising regularly, eating your veggies, and controlling blood sugar levels, cholesterol, blood pressure, and weight, scientists said, you might be able to reduce the risk of losing your mind. Researchers have also identified genetic risk factors, including three genes that lead to early onset of Alzheimer’s in some families, and one gene that has been linked to late-onset of the disease. But only half of those who develop late-onset Alzheimer’s have that gene, and not all who have the gene get the disease.

One possibility in the realm of Alzheimer’s research has sparked particular interest in the months since Ronald Reagan’s death: the use of human embryos as research material. With such prominent backers as Nancy Reagan and the Alzheimer’s Association, the push for federal funding of embryonic stem cell research has gained publicity. Many scientists favor the use of human embryos in research, but most readily admit that Alzheimer’s is one of the conditions least likely to be ameliorated by stem cells, because the disease is so complex and affects so many parts of the brain. Dr. Sam Gandy, an Alzheimer’s Association spokesman and scientist at Thomas Jefferson University who supports embryonic stem cell research, told the *Washington Post* that implanting stem cells in Alzheimer’s patients would involve “a zillion little surgeries” all over the brain—hardly a sensible solution or a silver bullet.

As scientists seek a cure and journalists hype even the least promising leads, we are realizing a sad irony about Alzheimer's: its prevalence is a side effect of our success. The public health and medical breakthroughs of the past century—from new vaccines and antibiotics to better treatments for heart disease and improvements in hygiene and nutrition—have allowed us to live longer, healthier lives. But progress has come at the price of our increased vulnerability to a disease for which the greatest risk factor is age. It is no coincidence that Ronald Reagan, our longest-living president, was also the first to be diagnosed with Alzheimer's. Consider the odds: At age 55, a person has a roughly one in 2,500 chance of developing Alzheimer's. At age 65, the likelihood rises to one in 100. At 75, nearly one in 10 have the disease. And by age 85, the odds shrink to nearly one in two. With the average American living 77 years today, nearly all of us are the potential victims of Alzheimer's.

'The Body Next to Me'

For the afflicted and their caregivers, an Alzheimer's diagnosis can be the worst of all worlds. It is a death sentence that arrives early enough to allow full comprehension of the devastation that lies ahead, but never early enough to avert it. Its onset is notoriously subtle: sufferers may notice that they walk into a room and forget why they are there or they cook a meal and forget to turn off the stove. The losses often occur over many years, and since they initially seem harmless—who hasn't forgotten to pay a bill or misplaced the car keys?—they can be easily overlooked. Eventually, the severity of the problem becomes obvious, as a woman gets lost walking on the street where she has lived for 40 years, or a man is asked for the time and realizes he can no longer make sense of his analog watch. These episodes often lead to the checkup that leads to the probable diagnosis: Alzheimer's disease. For the people on the receiving end of those two words, the terror is acute in this early stage, because they still have enough self-awareness to know that something is terribly wrong.

In the middle stage of Alzheimer's, they no longer possess that awareness. Sufferers recognize fewer loved ones, have hallucinations, and regress into a childlike dependence. They may get lost in their own homes, need help dressing, bathing, and toileting, and fail to remember major parts of their past or understand simple gestures and commands. Conversations with middle-stage sufferers are difficult, because they may no longer remember thoughts long enough to express them or recall questions long enough to answer them.

The late stage of Alzheimer's is probably the worst for caregivers and loved ones. In this stage, sufferers lose continence and the ability to walk by themselves. They may stare blankly into space for hours or curl into a fetal position for days. At the end, they may forget how to chew, how to swallow, even how to breathe.

The horrors of dementia leave many observers wondering if its victims are living at all. If a woman cannot remember her name or hold up her head, has she not become an empty shell of a person, and lost all quality of life? If a man can no longer control his bladder or recognize his wife, has he not lost his dignity and his very self? Can we really say that their suffering has any meaning, that their lives have any residual purpose or worth?

In fact, many who see the humiliation that Alzheimer's inflicts have come to believe that no dignity, no self, no personhood survives this dreaded disease. Media commentary after Reagan's death reflected this view. So do the comments of many in the research and advocacy communities, and many who have seen this disease up close, as it destroyed the minds and memories of their loved ones. Alzheimer's sufferers are frequently described as shadows of their former selves, husks that have been hollowed out by a disease that robbed them of nearly everything that once defined them.

Without their future or past, their judgment or reason, victims of dementia seem to float in a neverland while their bodies remain stranded in space and time. This dichotomy between cognitive absence and physical presence is perhaps the most disturbing aspect of Alzheimer's, causing onlookers to wonder if the person they once knew still exists, or if the plaques and tangles that choked off his memories have also obliterated his very self. One caregiver explained the dilemma well in Patricia Brown Coughlan's 1993 book, *Facing Alzheimer's: Family Caregivers Speak*. "Here's the body next to me," she said, "but we were alone."

Life Without Dignity?

Down through the ages, human beings have lamented the ravages of old age and the indignities of dementia. Yet dementia poses a particular challenge to us today, not only because of the increasing prevalence of the disease but also because of the type of disease that it is. The oblivion and dependence that dementia brings on are frightening prospects in a culture that exalts reason and autonomy, and often uses both to define our status as persons.

In the modern age, we often take for granted the idea that our minds are synonymous with our selves and our bodies are merely the matter that our

minds inhabit, with no intrinsic meaning or purposes of their own. We are, no doubt, obsessed with our bodies—we turn to cosmetics counters and plastic surgeons to perfect our physical appearance; we chase bodily pleasures with great vigor and little shame. We defend this right to bodily self-improvement in terms of our rational self-control. As persons who reason and will, we claim the right to do what we wish with our bodies. The only caveat is that we may not hurt anyone else—anyone, that is, who counts as a person with these same qualities of rationality and autonomy. Our dualistic assumptions underlie arguments for everything from legalized abortion (“my body, my choice”) and embryonic stem cell research (“it’s just a clump of cells”) to assisted suicide (“I have a right to die on my terms”) and cosmetic surgery (“I want the outside world to see the *real* me”).

The anxiety-ridden call to cure Alzheimer’s thus has two faces: a genuine compassion for those who suffer the depravations of dementia, and a creeping belief that life with the disease (life without autonomy) is not worth living at all. What pleasure, we ask, can there be in such a life? And how large a burden, we wonder, should the demented population place on the rest of us? Utilitarianism has become the default doctrine of our age—try to recall a recent public policy debate that did not include reference to a cost-benefit analysis—and it accords little value to the lives of the severely demented, who require so much care for a condition that leaves so little hope of recovery.

Australian philosopher Peter Singer has taken utilitarianism to its logical end, by defending the killing of those who flunk our society’s usefulness test. Singer argues that severely disabled newborns and adults who are mentally incompetent do not count as persons, because they are not rational, autonomous, or self-conscious. By contrast, Singer says, such animals as chimpanzees, gorillas, and orangutans possess these traits and so deserve more protection than some humans. In his *Practical Ethics*, Singer summarizes his argument against the lives of those who are conscious but not self-conscious—a category of “non-persons” that includes the demented. He allows that their lives may have some value if they experience more pleasure than pain, “but it is difficult to see the point of keeping such human beings alive if their life is, on the whole, miserable.”

Singer’s rhetoric has sparked widespread condemnation, both in America and abroad. His lectures in Germany and Switzerland have been met with heckling and boycotts; one protestor even tore Singer’s glasses from his face and smashed them. His appointment as an endowed bioethics professor at Princeton in 1999 ignited protests from hundreds of students

and advocates for the disabled and unborn, as well as from university trustee Steve Forbes, who withheld donations from his alma mater to demonstrate his disapproval. The fiery reaction against Singer's ideas suggests that our veneration for reason, intolerance of suffering, and disregard for the body has its limits. On some level, we still believe that human life is a mystery—and that we are not the ultimate arbiters of its meaning. We venerate reason and self-control as the defining qualities of personhood, but we seem unable to completely disregard the living, embodied, demented persons in our midst. Our real-life practice is often better than our philosophical theories. And our obsession with utility is still held in check by our willingness to love even those—or especially those—whom we are losing.

'There's Still a Loving Person in There'

As more of us experience Alzheimer's disease in our families and communities, our inchoate sense of the sanctity of human life may become more focused, and our defense of it more forceful. Theories that dismiss whole categories of humans as lacking dignity or personhood are tougher to swallow when the one you love is among those discarded. Even Peter Singer cannot seem to live up—or down—to his own standards. When his mother developed Alzheimer's disease, he did not refuse to support her "miserable" life or fight for the right to euthanize the "non-person" who gave him life. Rather, he and his sister spent tens of thousands of dollars to hire a team of nurses to care for her. In an interview for a 1999 *New Yorker* profile, writer Michael Specter pointed out the contradiction. Singer weakly attempted to justify it in utilitarian terms, noting that his expenditure "does provide employment for a number of people." Then he added this confession: "I think this has made me see how the issues of someone with these kinds of problems are really very difficult. Perhaps it is more difficult than I thought before, because it is different when it's your mother."

Indeed, it is. A vast gulf separates our public rhetoric about dementia from our lived experience. Though many caregivers conclude that loved ones in the late stages of Alzheimer's are no longer present in any significant way, others say the person they once loved still exists, and their interactions together still have meaning.

Ann Davidson is one such caregiver. Her husband, Julian, was diagnosed with Alzheimer's in 1986 at the age of 54. Davidson chronicled his journey through dementia in her 1997 book, *Alzheimer's: A Love Story*, and

shared her experiences with Michael Castleman, Dolores Gallagher-Thompson, and Matthew Naythons, authors of a 1999 guide to Alzheimer's titled *There's Still a Person in There*. In the guide, Davidson describes how she communicates with her husband, who no longer knows her name and has moved to a nursing home. "We continue to be deeply connected, to the extent that we can be, given his condition," Davidson says. "When I arrive, he smiles, runs up to me, and gives me a big hug. He's very affectionate and tender. We share lots of loving eye contact. We hold hands. He strokes my hair and kisses me." For Davidson, the physical presence of her husband is a consolation, the source of a connection that surpasses words: "We still communicate with looks, and caresses, and smiles, and laughter. It's taken a while, but I've gotten used to it. Odd as it may sound, we still have fun together." Davidson has learned from Alzheimer's "how much you can lose of what you once considered essential to your *self*; and still retain your humanity. Julian can no longer take care of himself, and he's down to just a few tunes and an occasional word, yet he greets me with a warm smile and a loving hug.... It's amazing to me, impaired as he is, Julian is still with me. There's still a loving person in there."

Davidson's insights are confirmed by many Americans who love and care for Alzheimer's sufferers, as well as by those afflicted with the disease. With the easing of the stigma that once left Alzheimer's victims and their families shrouded in silence, new voices are emerging to describe the disease from the inside. Their experiences challenge the conventional wisdom about Alzheimer's, suggesting that even those in its advanced stages can communicate at times, maintain a sense of self, and find meaning in their suffering.

Telling the Alzheimer's Story

Today, as more doctors diagnose Alzheimer's early and often, more of its victims can contemplate their fate and communicate their experiences before severe dementia sets in. This trend has led to the birth of a new genre of literature: First-person accounts of Alzheimer's written by those afflicted with the disease.

One of the earliest and most well known of these accounts is Robert Davis's 1989 book, *My Journey into Alzheimer's*. In the book, Davis records lucid reflections on daily life while he still can. "Perhaps explaining my feelings and emotions will give a glimmer of understanding to those who must care for my fellow-sufferers who can no longer explain their tortured feelings," writes Davis, a Miami pastor. "Perhaps I can still communicate so I

can give new hope and assurance to those faithful Christians whose former emotional feelings and blessings are being washed away by the start of this disease, and who are in spiritual despair because they are unable to understand what is happening to them.” At the opposite end of the spectrum, writer Thomas DeBaggio gives a decidedly grimmer account of the “parade of horror created by Alzheimer’s” in his 2003 book, *Losing My Mind: An Intimate Look at Life with Alzheimer’s*. DeBaggio documents his deterioration in meticulous detail, marveling at the strangely “liberating” quality of a disease that is “freeing me to float through life and stand on its head.” Chip Berger, a retired minister and social worker who posts his journal entries online each month, offers a similar abundance of detail about living with Alzheimer’s. Berger explains how it feels to walk into a room and not know why he is there, put a pill into his coffee instead of into his mouth, and surrender his razor to his wife because he no longer knows how to shave. He offers an inside look at the subjective experience of losing one’s mind. “As the moments and days fly by and I have little memory of what has or is happening to me,” Berger says, “[the moments] don’t seem as long.”

These first-person accounts are as puzzling as they are illuminating. They combine a penetrating self-awareness with an image of the ways that dementia erodes that awareness. And they reveal the ways in which the loss of some forms of consciousness may awaken new ones—new ways of being in and beholding the world.

Such articulate expressions are more rare in the advanced stages of Alzheimer’s, when verbal communication becomes difficult. In *Creating Moments of Joy*, author Jolene Brackey, who has worked as an activities director at an Alzheimer’s day-care center, advises caregivers to stop trying to talk their loved ones back into sanity or correct their mistakes. Instead, Brackey says, caregivers should look for new ways of communicating and appreciate the new levels of intimacy they can yield. A case in point: The conversation recorded between Harold, a father with Alzheimer’s, and Jean, the estranged daughter he was no longer able to recognize. Harold thought he was talking to a stranger when he told Jean that he had a daughter he loved very much and he wished she knew it. With tears in her eyes, Jean answered: “She knows, Dad, she knows.”

Several studies confirm the residual communication skills of even those dementia patients who can no longer speak. A 2002 study published in the *Journal of Aging Studies* found severely demented patients in Scotland and England using non-verbal behavior to connect meaningfully with others. By touching someone on the arm to get attention, leaning

in toward a speaker to show interest in a conversation, or holding out a hand to show off a set of newly polished fingernails, dementia patients with severe aphasia still managed to communicate. The study's authors—Gill Hubbard, Ailsa Cook, Susan Tester, and Murna Downs—reported that the patients “acted in the context of shared meanings, possessed a ‘self,’ and took on the ‘role’ of others.”

Dementia sufferers often experience their selfhood in the same way that they communicate their thoughts and feelings—in and through their bodies. Two research papers published in 2003 in the *Journal of Aging Studies* recently confirmed the importance of embodiment to the identity of Alzheimer's sufferers. In “‘The Painterly Hand’: Embodied Consciousness and Alzheimer's Disease,” social scientist Pia Kontos cites examples of Alzheimer's sufferers who have retained aspects of their individuality even in the last stages of the disease. She considers cases like that of Willem de Kooning, a painter who produced acclaimed works of art despite his dementia, and Iris Murdoch, a writer who preserved her knack for greeting visitors warmly and pretending to follow their conversations in social settings even after she could no longer understand what they were saying. Kontos sees both cases as evidence that “the self is not exclusively constituted by cognition but involves bodily knowledge.” In considering the personhood of dementia patients, Kontos says, we cannot ignore “the embodied nature of the self.” Alison Phinney and Catherine Chesla came to similar conclusions after interviewing Alzheimer's patients and their caregivers for their study, “The Lived Body in Dementia.” The complaints of Alzheimer's sufferers—about “being slow,” “being lost,” and “being a blank”—convinced the authors that Alzheimer's is an “embodied experience,” not simply the breakdown of “a disembodied mind.” They conclude that speaking about dementia symptoms “solely in terms of the dualist categories of mind and body is to perpetuate something of a misunderstanding of the lived experience of dementia.”

Alzheimer's disease exposes the flaws inherent in locating the self exclusively in the mind and assuming that only those with awareness and memory are persons. As ethicist Gilbert Meilaender wrote recently, in a paper presented to his colleagues on the President's Council on Bioethics, “one might take the living body, not the immaterial will or the power of choice, as the locus of personal presence.” We are not minds alone or bodies alone, but “embodied souls” and “ensouled bodies.” To understand this truth is to understand the dignity of those whose minds are fading, but whose presence as persons can never be in doubt. Those with Alzheimer's

disease remind us most vividly that our humanity comprises both our bodies and our minds, and perhaps something else that transcends them both.

The Spiritual Dimension

While scientists and philosophers debate the relative importance of the body and the mind for personhood, those suffering from the disease often focus on another matter entirely: the state of their souls. Spiritual themes abound in the first-person accounts of dementia patients and their caregivers, and those impacted by the disease often draw on religious concepts to find meaning in their suffering.

Stephen Post, a bioethicist who has researched this phenomenon, estimated in a recent *First Things* essay that 90 percent of dementia patients pray. He said many of his research subjects undergo a religious conversion after they receive an Alzheimer's diagnosis. Post offers as proof the testimony of Peter, a Roman Catholic who began to pray daily after his diagnosis. "I've come to the conclusion that everything has a purpose," Peter says, "... maybe this was to slow me down to enjoy life and to enjoy my family and to enjoy what's out there. And right now, I can say that I'm a better person for it, in appreciation of other people's needs and illnesses, than I ever was when I was working that rat race back and forth day to day." In his contribution to the 1996 book, *Birth to Death: Science and Bioethics*, Post tells the story of another research subject, a woman named Jan who had been diagnosed with early-onset Alzheimer's disease at age 41. Though fearful about what awaits her, Jan said she is rediscovering life's simple joys and finding meaning in her suffering. One morning, while her son shoveled snow, Jan felt suddenly compelled to run out to join him. "I had truly forgotten what a beautiful sight a soft, gentle snowfall could be," Jan says. "As I bent down to gather a mass of those radiantly white flakes on my shovel, it seemed as though I could do nothing but marvel at their beauty. Needless to say [my son] did not share in my enthusiasm, to him it was a job; but to me it was an experience." Jan believes that God allowed her the gift of seeing the snowfall as a child does—a gift that came not in spite of her condition, but because of it. "Jan is still here, I thought, and there will be wonders to be held in each new day, they are just different now."

The heightened spiritual sense that follows a dementia diagnosis often lingers long after other memories and impressions have faded. Even those in the advanced stages of Alzheimer's may remain remarkably lucid about core religious beliefs and retain an almost intuitive knowledge of the reli-

gious rituals that shaped their lives. Caregivers tell stories of severely demented loved ones who no longer know the names of their children or where they are, but still recite flawless rosaries, sing rousing renditions of “Amazing Grace,” or respond with reverence during the candle lighting that ushers in the Jewish Sabbath. Recognizing this attraction to the transcendent, many nursing homes and adult day-care centers are incorporating religious symbolism, songs, traditions, and liturgies into their activity schedules for dementia patients.

Caregivers also rely heavily on faith as they accompany their loved ones through the dark night of dementia. In a study published five years ago by the Chicago-based Park Ridge Center for Health, Faith, and Ethics, more than four in ten rural caregivers reported that religious activities are most helpful in allowing them to cope with Alzheimer’s, and two-thirds said they rely “heavily” on prayer. Most of the caregivers said they believe God answers their prayers and that their prayers gave them peace, strength, and even answers to specific caregiving problems. The study found that the duration of the disease affected the intensity of caregiver reliance on prayer: The longer it lasted, the more caregivers depended on divine providence.

A turn toward God amid terminal illness is certainly not peculiar to dementia patients and their families. But the losses triggered by Alzheimer’s—both of past memories and future plans—lend a particular poignancy to the spiritual sense and transcendent vision of those afflicted with dementia. As we consider the meaning of this type of suffering and how it relates to personhood, we should not neglect the spiritual dimensions of this disease. And we should not ignore the voices of dementia patients and their loved ones, who sense that something profound is happening just beneath the surface of Alzheimer’s—a process of detachment and discovery that is central to the mystery and dignity of the human person.

A Meaningful Death

None of this alters the agonizing realities of life with dementia: the regression of adults to a state of child-like dependence, the sorrow of no longer sharing life with a parent or spouse the way we once did, and the degradations of the body as it finally fails.

But even in its deprivations, Alzheimer’s can awaken those who are touched by it to some of the deeper human truths. Dementia reminds us of our weakness and interdependence. Its attacks on the mind invite us to reconsider the significance of the body. Its devastation of the memory

forces us to reside in the moment. And its indignities remind us that we have a deeper dignity, one rooted in something more fundamental than our reason, will, or self-awareness.

Ronald Reagan, perhaps the most famous casualty of Alzheimer's disease, was thought by many to have lost his dignity in dementia. Indeed, many said, he lost his very self. But the story of his last moments suggests otherwise.

On the afternoon he died, Reagan opened his eyes for the first time in five days and looked directly at his wife. He did not give her the blank stare typical of a man in the last stages of Alzheimer's. Instead, his daughter Patti Davis reported in *People* magazine, his eyes "were clear, and blue, and full of love." Davis says her father gazed at her mother "for a good minute. He saw her, there was no doubt in my mind. It was as if his soul was saying, 'Hey, I was never really affected by all this.'" A moment later, Reagan breathed his last.

Nancy Reagan told her family that this last look of recognition was "the greatest gift he could have given me." Her husband's physician, Dr. John Hutton, said on MSNBC that he could not exclude the possibility that Reagan recognized his wife: "Whereas one could not explain it on any medical or physiological terms, I think there must be something to this."

The story of Reagan's final flash of awareness did not stop many pundits from describing the former president's death as devoid of dignity, an anticlimactic end to a life that had long ago ceased to matter. But Reagan's relatives seemed to disagree. His wife's grief at his physical death, and his family's joy at his last flash of awareness, suggest that beneath all of the confusion and loss shrouding Reagan in his last days, a fully human person remained to the end. According to Davis, her father did not die a "horrible and depressing death," as one commentator described. Rather, she said, "If a death can be lovely, his was."

At the presidential library and museum where Reagan is buried, a curved wall is inscribed with comments he made at the library's 1991 opening. The inscription reads, "I know in my heart that man is good. That what is right will always eventually triumph. And there's purpose and worth to each and every life." In reflecting on the purpose and worth of Reagan's life, and that of all Americans afflicted by Alzheimer's, we should heed the former president's parting words. The man who brought Alzheimer's out of the shadows a decade ago has left us with a conviction that echoes the one our founding fathers enshrined in the Declaration of Independence, the self-evident truth that all are created equal, endowed

by their creator with certain unalienable rights. As the Alzheimer's epidemic leads us to consider the source of our human dignity and probe the parameters of our personhood, we would do well to remember that radical truth upon which America was founded. And we would be wise to resist the temptation to exclude anyone—even the most severely demented—from its protection. True compassion demands no less.