

PATTERNS OF ETHICAL DILEMMAS  
FOR CAREGIVERS OF PERSONS  
WITH SENILE DEMENTIA  
ALZHEIMER'S TYPE

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I've been asked to talk about ethical dilemmas arising in the care of those suffering from Alzheimer's Disease, and I thought it might be useful to do so by talking about the kinds of ethical dilemmas that arise for care-givers of such patients. One of the striking things that emerges from this approach is that, as diseases have their medical courses, so, too, they have their ethical courses. I have long been a champion of what I call "preventive ethics," involving anticipating in advance the types of ethical challenges that are likely to arise in the ethical course of a disease. It is my hope today to illustrate this approach through the discussion of a number of concrete cases, gleaned from extensive conversations with family caregivers of such patients as a part of a research group in which I participated over the past three years at The Hastings Center, a Bioethics "think tank" North of New York City. I have divided my discussion into four parts, reflecting a somewhat arbitrary division of the disease into early, middle, late, and final stages.

## THE EARLY STAGES OF THE DISEASE

Typically, a diagnosis of Alzheimer's is reached after an individual begins to manifest symptoms. "He's getting a little forgetful" is a phrase that often signals to a physician a family already dealing with the symptoms of the disease: short-term memory loss, occasional transient bouts of confusion, inexplicable loss of an ability, etc. These early stages are often accompanied by denial, compounded in the elderly patient by the widespread belief that these kinds of symptoms are natural accompaniments of old age, and in the middle-aged patient by embarrassment, social isolation, and fear (for example, of loss of income or abandonment).

Incidentally, I think we will begin seeing a different phenomenon as our ability to detect the genes responsible for some of the forms of Alzheimer's type of dementia increases. Indeed, even now, those of us who have had afflicted relatives, because of the "geneticization" of our thinking about this disease, wonder whether we will be afflicted and may subject ourselves to whatever early diagnostic tests are available. Just as denial can delay the pursuit of counsel and treatment, so premature anticipation can distract a life from the comfortable pursuit of meaningful activities. As we contemplate the growing power of medicine to tell us what we will suffer and even when we will die, we are left to ponder anew the old adage, "Where ignorance is bliss, 'tis folly to be wise."

In thinking about my own experiences, in reading and talking with other persons about theirs, I have come up with three areas of ethical problems as patients and their caregivers come to terms with the realization of an Alzheimer's diagnosis. These areas involve: (1) questions of openness versus secrecy and even deception, (2) problems of advance planning of financial affairs but also of confronting questions of preferences to be expressed in advance directives and

instructions to proxy decision-makers, and (3) perhaps the most fundamental issue of all, questions of who will be the primary caregiver, what role others will play, and the impact on the interests of other members of the caregiver's immediate family.

Individuals and their families differ, of course, widely in their reaction to receiving a diagnosis of Alzheimer's. As with other terrible news, there is often an urge to protect the patient or other members of the family from the grim news. In my own case, my parents lived with that diagnosis of my mother's Alzheimer's disease without ever communicating it to their children. Yet, we knew of Mom's progressive decline, but reacted to it with encouragement that she take a memory improvement course. I spent long hours during family visits to Oklahoma explaining association techniques, oblivious to the impossibilities of what I was asking. The implicit message was that I thought she was becoming intellectually lazy, that her memory lapses were "her fault" and able to be fixed with her efforts.

It is commonplace for the afflicted to experience shame and embarrassment, and for their families to adapt to their lapses and increasingly fill the shrinking social circle. Consider the story of Emily Sidgwick, taken from the third chapter of a new book under preparation by James and Hilde Lindemann Nelson:

Emily Sidgwick is fifty-seven, but she could easily pass for ten years younger. It's not that she's ever worked hard at looking young. In fact, she's always had an air of formality about her, a certain way of dressing, walking, and talking that can make a person seem more mature than she really is. When she reached her fifties, she took secret satisfaction in finally having "grown into" her personality....

After spending her youth and her early middle age caring full-time for her family and house, she's devoted the last decade to fulfilling a lifelong ambition to become a professional free-lance writer. She takes a deep satisfaction in being able to express herself in a variety of ways and prizes her independence even more than she thought she would--especially since writing has finally started to pay her a reasonably comfortable income.... Ms. Sidgwick has been through a lot in her life--a nasty divorce and a bout with breast cancer--but lately she's been relaxed, confident, and successful, and the people closest to her have tended to smile when they think about her and how nicely her life has come together.

That's why it wasn't just devastating but also painfully ironic when the symptoms started showing up. Ms. Sidgwick thorough shocked her daughter, Fiona, when she started to eat without a knife and fork one evening. And because it was so completely out of character, she worried her friends when she began to be late for appointments because she somehow lost her way.

But if her friends saw these episodes as cause for concern, Ms. Sidgwick saw them as horrifying and absolutely intolerable. She couldn't stand the embarrassment. Besides, she didn't want to upset her friends and acquaintances any more than she already had. So quietly that most of them failed to notice at first, she began to turn down their invitations and spend more and more time at home. She limited her research and interviewing, and started to find reasons to refuse writing opportunities. She began to cut the ties that bound her to a life she had cherished.

She couldn't so easily avoid Fiona, who has been living with their mother in the

aftermath of her own divorce. But she did her best to avoid situations in which Fiona might have to "make allowances" for her. Unfortunately and inevitably, her best hasn't been quite good enough, and Fiona has had to make adjustments to the changes in her mother's abilities. Things have now reached the point where these allowances and excuses are becoming second nature to Fiona--so much so, in fact, that most of the time she hardly notices she's making them. For the last several months Fiona has convinced herself, almost, that there isn't anything really so odd about Mother's behavior. She firmly believes this--except perhaps late and night, when she wakes, worries, and finds it hard to go back to sleep.

As Ms. Sidgwick has less and less to do with people outside her home, she grows more and more dependent on Fiona to fulfill her needs for companionship. Already, Fiona too is seeing less of her friends. She's not as likely to go out in the evenings. Even visits with her sister Reneé and her brother Nicholas and their families have fallen off. Like her mother, Fiona is losing some of their own connections with life. The moments when she feels overwhelmed are happening more and more often, and she finds herself standing in front of the window display at work staring at nothing, her mind as blank as her morning. Alzheimer's disease is starting to claim more than one victim in this home.

An ethical analysis might identify several factors in this story as contributing to the decline of the several lives it touches. The lack of openness about the problems--meeting changes in her behavior with embarrassment, and turning away from contacts with others--all are indications of

the insidious nature of deception and concealment. Tom Kitwood recommends the four A's as the best way for Ms Sidgwick and those who love her to respond to the changes she's undergoing: acknowledgement, acceptance, affirmation, and adjustment. Shame and embarrassment are ways we have for taking responsibility for what we do. One who feels responsible is not inclined to seek out a medical diagnosis: if it's just me, getting careless, no doctor is going to help! Often, delays of a year or more accompany these feelings, and the hesitancy to trade uncertainties about what is happening for some set of grim realities often results in substantial delays in seeking medical counsel. It also delays adjustments that can be made, adaptation of family and friends to the predictable realities of the disease. Ms. Sidgwick and her children need a great deal of information to enable advance planning while she is still able to participate significantly.

Some have argued that the most moral thing to do is to deceive dementia patients about their diagnoses. In 1993, Dr. George Markle, a physician from New Mexico, wrote a letter to the New England Journal of Medicine concerning his wife's death from Alzheimer's disease.

When it became clear that my wife had Alzheimer's disease, I decided to tell her that she had a condition of forgetfulness and that she was no more to blame than a person with heart disease or arthritis. I shielded her from television programs and articles that discussed her dismal future. While still rational, she went along with making a living will and giving me power of attorney because I did the same at the same time for her. There was therefore no reason to cause her to suffer the dreadful anticipation that she would otherwise have had to bear. (NEJM 327(10)(11 March

1993):736)

This strategy would never have worked with Ms. Sidgwick, who had already seen the television shows and read the magazine articles, and knew what she was afraid and ashamed of. It's likely too that Ms. Markle had seen them too; if so, her husband's attempts at shielding her would be the very things that kept him from giving her the special kind of support that comes from talking things over with the person you love best. Repeatedly we learn in medicine of diagnoses that the patient and the family attempt to keep secret from each other, each knowing the diagnosis but believing the other doesn't.

One of the most pernicious consequences of secrecy and attempted deception is that frank discussions of the future realities of caregiving cannot be held by people who are actively at work denying that future. In the case of Ms. Sidgwick, Fiona became the primary caregiver by default. Her move in with her mother, a transitional move out of a failed marriage and into a as-yet-to-be-determined future, became transformed by default into a long-term 24-hour-a-day commitment. Fiona needs her brother and sister to share the responsibility that she is shouldering. Their detachment makes it all too easy for them to be critical, or, worse, for them to throw up their hands and say to their sister that they will go along with any decisions she wants to make. In both these attitudes there is a betrayal of the loving requirements of members of the family. René and Nicholas, as well as Fiona, need their mother: need her as one to whom to return her love and care when they were young. The requirements of that kind of devotion are great, and they come not in a contract but in the way the existentialists call "thrownness." We are "thrown into" the responsibilities of adult children with dependent parents,

just as we were "thrown" into the world as dependent children to begin with.

A final danger this family is in the tendencies of families simply to expect that one member--usually a woman--will be the "primary" caretaker. The others then take less active roles, deciding for themselves, privately, how much or how little they're going to do. This, of course, is a good way to breed resentment, ill will, and defensiveness. While in practice it's unlikely all the tasks can be divided evenly among all the family members, an open determination of what will count as fair and what members can expect of one another, and for what periods of time, is a chore that needs to be undertaken early on.

A final set of ethical problems brought on by this disease arise, I think, from a combination of its inexorability and the corrupting influence of loss of capacity of the loved one on those thrust into the roles of caregivers. A young friend, in her late twenties, recently confided to me that her father had for some time been showing signs of dementia, and had recently had a fall, breaking a hip. Placed in a nursing home after recovery, he exhibited a considerable and persistent loss of mental abilities. His children decided that he wasn't going to improve appreciably, and got him to sign a durable power of attorney to one of his children who was a lawyer. They then devised the following plan: his assets would be distributed immediately to his children. They would then wait the required three years, covering the costs of his care from what were now their own assets. At that point, when they anticipated that a substantial portion of his assets would still remain intact, they would have him declared indigent and transfer the cost of his care to Medicaid and Medicare.

My suspicion is that this fraud seemed justified to them because they had thrust upon them at a time and in a manner not of their choosing responsibility for his care. His vulnerability

they saw as an unwelcome dependence on them for which they deserved every compensation possible. Faced with the option of either covering his care with his assets until they ran out (what the law requires) or doing what they did, they took the course of action that would provide them with a compensation for the disruption caused by assuming responsibility for a suddenly dependent parent. His failure to anticipate his own possible final chapter, and provide for it appropriately--by no means a simple task--put them in a position that encouraged a kind of anonymous, indirect predation on the rest of us who fund these social programs, frustrating the terms of the social contract into which we entered when this legislation was passed.

### **THE MIDDLE STAGES OF THE DISEASE**

Three groups of moral problems characterize the middle stages of dementia diseases. They center around conflicts between the desire to preserve the dignity of the afflicted and protecting his or her safety, negotiating desperate demands for unreasonable promises, and the old issue of truth-telling versus benign deception.

I think of dignity in very practical, pragmatic terms. A person is stripped of dignity when he or she is stripped of the ordinary exercise of his or her skills of daily living. Eventually this disease will do just that, reducing the afflicted to a helpless, incontinent, infantile shell of a former robust self. But there are ways we inadvertently may "cooperate" with the ravages of dementia, in our efforts to protect the afflicted from harm. Here are some stories of a couple that had to cope with these problems.

Harry and Ann Fisher had enjoyed a division of labor for many years in which Harry "brought home the bacon" and Ann "fried it," so to speak. Harry was a factory worker in a Ford plant, worked overtime frequently, and brought home a good paycheck.

Ann assumed the responsibilities of raising the kids, keeping the home, paying the bills, and managed to do that while maintaining her good looks and grooming. Harry was not an emotionally demonstrative man, but he quietly enjoyed Ann's competencies and the ability to relax when he came home.

About the time Harry reached retirement age and started the transition to home handyman and gardener, Ann began to show the early symptoms of dementia. Her ability to keep the family checkbook straight suddenly left her, and Harry had the embarrassment of a couple of months of bounced checks and overpaid accounts. Ann called him on several occasions, having gotten disoriented and lost while driving; once a policeman brought her home, having stopped Ann as she weaved down the street peering from side to side in a vain attempt to locate a familiar landmark. As he handed Harry the address of the garage where her car had been towed, he raised his eyebrows pointedly as if to say, "She'd better not drive any more." And Harry was shocked one evening to see the mess Ann had made of trying to put her lipstick on in preparation for going out to a movie.

Harry raised the question with his wife of driving, only to find that she felt perfectly safe driving and still took great pleasure in it--apart from the tendency to get lost. His way of coping with her limitations was to get her to agree that whenever she went someplace, he or a friend would ride along and help her with directions. Harry knew that there was probably a somewhat elevated risk of her having an accident, but she seemed reassured by having an attentive navigator, and as long as she didn't seem to be a threat to others, he resolved to let her continue driving.

The question of her continuing to pay the bills was a more serious matter. It obviously gave her more pleasure than frustration to continue this practice, but he didn't want their credit rating to take a nose dive. Harry visited each of their regular accounts and explained that they would be getting two checks each month: one from her, with the word "VOID" written inconspicuously across the back, and one from him for the correct amount. Her checks were to be quietly put aside. Harry even got a set of special checks printed with VOID on the back in a not-very-noticeable blending into the design, and Ann never noticed the difference.

The lipstick problem showed Harry's greatest inventiveness. Harry took his wife's lipstick and closed himself in the bathroom. For hours he practiced putting on lipstick himself, until he got the knack of it. Then he suggested to Ann that he'd like to try putting it on her, just to see if he could do it. Remarkably, she took the suggestion with graceful amusement, liked the result well enough, and gave him the job "in perpetuity."

Each of these situations involves in some way both the compromises by the disease of Ann's dignity and Harry's efforts to adapt to those compromises without increasing them. The decisions regarding driving were in some ways the hardest, because Ann's -- and others' -- safety was potentially involved. Harry's reasoning was classic risk/benefit balancing: the residual risk that remained after Ann's agitation at getting lost was minimized by having a navigator with her was not yet, he judged, great enough to justify taking away her keys. Ann's ability to "pull her own" with him and with friends was exceedingly important to her, and he was unwilling to deny her

that responsibility unless and until she became a genuine hazard.

In other ways the trick with the checks was harder, for it was the first time Harry had ever deliberately deceived Ann. It bothered him to have created a tangled web of deception, with others co-opted into it in the service of preserving the appearance of her financial management. Unlike his approach of her friends to assist in her driving as navigators--a genuine effort to maintain a useful function--this deception was all sham, and he feared her discovery of it and the subsequent confrontation. Fortunately, her frustration at being unable to get the checkbook reliably to balance provided him with the opportunity to offer to take over that chore in exchange for her help with a gardening project, and she accepted with apparent relief.

The image of a somewhat gruff, strong-and-silent type practicing putting on lipstick behind a firmly closed bathroom door strikes us as at once funny and wonderful. Here was a simple act of accommodation that enabled Ann to step forth proudly and to avoid public embarrassment. At the same time, the simple intimacy brought to their relationship a kind of quiet joy that neither had known for years. I'd say Harry gets two As and a solid B on his moral report card!

Families need to know that products have been developed that ease these middle stage risks. There are now stoves whose burners automatically shut themselves off when the temperature begins to climb toward dangerous levels in a forgotten pot. Tubs and showers can be replaced with ones in which the chances of falling are greatly reduced. Security alert systems that are voice activated are available. A substantial amount can be done to protect the progressively demented and to prolong their period of relatively safe independence.

Perhaps the cruelest middle stage theft by Alzheimer disease is the lost of short-term

memory. Consider the story of Barbara Fitzgerald, as told by the Nelsons:

An exhausted, middle-aged woman stands in the bedroom doorway as the gray light of early morning outlines her father, asleep under the quilt. Barbara Fitzgerald is just about drained. As she pulls her robe more tightly about her, she feels that in this gesture she is also holding herself together. Her dad, diagnosed several years ago as having Alzheimer disease, is starting to stir, and she is dreading the moment when he will awake.

Mr Kessler begins every morning by sitting up in bed and asking for his wife, who has been dead these twelve years. Barbara has learned the hard way that if she tells him the truth, however gently, however matter-of-factly, her father's grief will be as intense as if the loss were fresh. To him it *is* fresh, every time. Yet if she tells a lie--if she says that her mother is out shopping, or visiting, or at work--she may have to fend off his inquiries all day long, piling other lies on top of the first one. Her father is not so demented that he accepts what he's told without question; if she lies he'll be suspicious and sometimes flat-out nasty, blaming his daughter for keeping his wife from him.

Barbara is profoundly tired of wrestling with this problem, and with all the other problems as well. The refrain that's been running through her head for months starts up again: Dad really should be in a nursing home. But shortly after he was finally diagnosed, he asked her repeatedly to promise that she would never "turn him out of his own house." She gave him her word, and meant it then. Of course, when she made

that promise, Barbara didn't know what she knows now about how hard it would be to take care of him. She also didn't know that she'd be facing this life without her own husband, George, who left her two years ago to marry a woman who is both younger and unburned by a demented father. And while she didn't have great hopes of her brothers, she didn't think that they would leave virtually all of Dad's care to her.

The first rays of sun break through the window, and her father opens his eyes.

The two complex moral dilemmas this story poses are those of lying versus seeking to protect from pain, and promises one has made without a full picture of their implications. But as well, there are the failed relationships with her ex-husband and with her brothers.

Family caregivers have to weigh skillfully the conflicting needs and interests of those they are caregivers for, but also to be equally skillful at balancing what is due their loved one with what is due to themselves; and finally, they also have to give due consideration to the needs, desires, interests, and claims of other family members who are not demented.

Barbara's husband George apparently didn't feel that she was able to do a good job at this. If you ask him, he'll say she left because Barbara's devotion to her father was eating up so much of her time and attention that it effectively ended their relationship. Barbara herself, of course, has another view of the matter: George kept his promises of fidelity "for better," but he lacked the backbone to honor them "for worse." There are times, though, when she feels not only angry at her family for letting her down, but angry at herself for allowing so much of her life to be consumed by her father's care. And she is struck by the irony of her unwillingness to break a promise not to institutionalize her day, which she powerfully wishes she hadn't made, and

George's willingness to break a promise to stick by her through thick and thin, also made in blissful ignorance of what was to come.

Similarly, Barbara had accepted without question her primary caregiver responsibility for her father, expecting that her brothers would be appreciative and supportive in many ways. Instead, she has discovered that they share the attitude that it's her just desserts for being Dad's favorite when they were young. Besides, they think she underestimates how sick he really is and what he needs, holding that he really can't tell the difference between living at home and living in a long-term care facility.

These are issues that cannot often successfully be resolved through indirect mechanisms of mutual trust and willingness to be supportive. Even in families with strong ties, negotiation of responsibilities and expectations has to occur in order to avoid the breeding grounds of resentment and contempt. The tasks involved in caring for demented people are burdensome enough without costing caregivers some of their most precious possessions--good relationships with other people they may have known and loved all their lives. The task, then, is to have discussions over such difficult matters that are productive, practical and healing, rather than divisive.

The dilemmas of deception and promise-breaking that feature so prominently in this story hint at a deeper, underlying common theme. One suspects that the demand that he would never be institutionalized was made by a father of his daughter in full knowledge both of her vulnerability to such requests and with some sense of how burdensome his care was to become. One may question the decency of a parent who would do that. The sense, though, is that the importance of keeping that promise as his dementia progresses is greater to her than it is to him.

And, she may need help in seeing that the logical conclusion of her complete unwillingness to rethink the commitment could be that they both would end up "turned out of their home" if her ability to sustain the strain of his care fails completely. Better that he be institutionalized with a whole daughter to assist in that process than that his institutionalization be occasioned by her collapse. We should take seriously the symbolism of Barbara's pulling her robe more and more tightly about her.

### **THE LATE STAGES OF THE DISEASE**

Let us return to our story of Harry and Ann.

One day Harry and Ann had gone to the super market, Ann proudly maneuvering the car into the parking lot. They were inside, and Harry as usual brought over various items to consult with Ann about whether they sounded tasty to her. Suddenly and without warning Ann started to scream at him, yelling that he was bothering her, that she didn't know what he wanted, calling for help and furiously pounding the grocery cart against his shins and outstretched hands. Shaken, Harry withdrew, explaining to onlookers that she was his wife and that she had never acted like this. Moments later the storm had passed, and Ann chided Harry for keeping to himself and ignoring her.

It is the prospect of these sorts of personality changes, in which, temporarily or permanently, a beloved relative no longer recognizes loved ones, that so terrifies the knowledgeable when informed of the diagnosis. We are defined by our loving relationships, our career activities, our interests, so that the prospect of our loss of consciousness of those defining relationships,

activities and interests, and especially of the substitution of a persona that may well act out of character in bizarre ways, strikes us as horrific. We feel that we are to be possessed--of which we have an age-old fear and loathing.

For loving caregivers, equally the hardest task throughout the long course of dementia's decline is maintaining loyalty to "the Stranger" that steals the mind and character of the loved one. For the twists and turns of the progressive destruction of the brain often release behaviors and appetites that are suppressed so successfully in the "whole" person that their existence beneath the surface is never suspected.

I had the experience of my 91-year-old, proper Victorian mother, whom I never saw in the same bed as my father, of whom my brother and I had reluctantly concluded as the result of our appreciation of the facts of life must have had sexual relations twice, propose to me that we revisit her old apartment so "we could go to bed together." Learning years later from a kind physician that she must have had a small frontal lobe stroke helped me "forgive" the incident, but I found it increasingly difficult to maintain loyalty to the stranger who occupied her body, who did not recognize me as her son, who did not remember my calls or visits from one hour to the next.

The loss of a sense of connectedness, in some ways, makes the institutionalization of the demented easier. It also raises profound questions about the nature and validity of advance directives. For, one might say that the person who indicated her wishes about care when she could no longer competently express them is in important ways not the person for whom those directives appear now to have been issued. We must hold fast to some kind of relational analysis of the self if we are to avoid the metaphysical morass here. Even though such familiar markers

of identity as continuity of memory, recognition of self- and others are long gone, it is still that being who gave birth to me these 45 years ago that is before me now. Caregivers need help in remembering the basis for maintaining loyalty to The Stranger that the Alzheimer's sufferer becomes.

In listening the families discuss the myriad conditions under which they decided to institutionalize a loved one in a support group associated with the writing of the Nelson's book, I was struck by the complexity of this process being exaggerated by being left to "the last moment," and by the wisdom of my parents in arranging for their situation well in advance of the need to avail themselves of it. For their approach was to locate and move into a "life care community" -- a cluster of condominiums and apartments situated around a skilled nursing facility. A variety of services were available in apartments, from cleaning and laundry to food delivery. They were able to maintain independent living until my father's death. My mom, after attempting to continue for a few months, moved into a single room, furnished with her own things, in the SKNF. As her end-stage dementia approached, she was moved into a semiprivate hospital-style room, where she stayed until her demise.

Decisions to institutionalize are often made after some incident in which the afflicted is harmed. The search is often for a nursing facility to transfer the loved one into from a hospital room. There is little time to conduct a proper search, to develop potential relationships with staff, to provide orienting visits. Afflicted relatives are often acutely aware of their differences from nursing home populations, unaware of their similarities. The decision to institutionalize is often a time of severe recrimination of the primary caregiver, who frequently gets it both from the afflicted and from siblings and other relatives who have not borne the burdens of daily care.

And, it is clear also that, as a society, we have much to do to make institutionalization a transfer of the afflicted one to a different life and not merely to a warehouse. I have been struck by the importance of communicating to institutional caregivers the story of the life entrusted to their care. And sometimes the questions of identity arise most acutely just at this point of entry. The Nelsons write:

. . . people are more than their diseases, and as the person's own ability to assert the fullness of his life and personality faces, preserving his social, and not just medical identity becomes more and more the job of those who love and care for him. . . . Steven Sabbat and Rom Harré, in their article, "The Construction and Deconstruction of Self in Alzheimer's Disease" (*Ageing and Society*, 12 (1992): 443-461) report that someone introduced a sufferer of the disease to a new acquaintance by saying, "This is Henry. Henry was a lawyer." Henry gently interrupted: "I AM a lawyer." Henry was fighting to maintain his sense of self--an extremely precious value--against the incursions of his disease. His companion missed an opportunity to be his ally in this struggle.

The ethical problems of medical decision-making about the treatment of terminally ill Alzheimer's patients are pretty familiar. Indeed, the Buffalo General Hospital Ethics Committee case load is dominated by these cases--cases of writing DNR orders, of withholding or withdrawing feeding tubes, of whether the dehydration and starvation that comes with suspending nutrition and hydration is in fact painful or not. Much has been done in the institution to ease the tasks of

families and other caregivers in making these decisions, and much more will be done.

I think, however, that as a society we have a much greater moral struggle to come to terms with the kinds of situation in which Dr. Kevorkian has been so prominent. As people become more aware of their likely cause of death, and particularly as they become more aware of the kinds of changes that the dementia diseases wreak in their personalities and relationships, increasing numbers will demand the option of an early death with the assistance of their caregivers. And, the reasoning of the caregivers themselves, burdened with promises they seem increasingly unlikely to keep, show more profoundly than words can perhaps reveal how very much Alzheimer's disease is a disease of the family, not just of the afflicted. Let me recount a final story.

Ever since Wilma's diagnosis some years before, her husband Jack had been a devoted and loyal caregiver. He had arranged their affairs so that, as their years advanced and he became unable to provide her with the fullest of care, there would be others to assist. He had moved them into a life care community. He had continued their traditional breakfasts, had endured Wilma's increasing garrulousness, and had quietly shared in the increasing isolation without complaint. He had maintained appearances, had covered for Wilma when she was unable to remember a name or recognize a face.

Wilma was excessively anxious about being "left alone" to cope with her new life, and she exacted a promise from Jack that he would not die first. He made the promise to her, realizing that it gave her great comfort, knowing of the difficulty that

keeping it might bring.

Jack's health declined; he began to suffer from congestive heart failure. He sensed that his end was near. One evening his son, who lived 1500 miles away, received a call. Jack reminded his son of the promise and said, "I'm afraid that I am going to be unable to keep it, unless we can figure out a way for us both to die at the same time. Nothing violent: no guns. Can you help us just go to sleep and not wake up?"

Shocked and stunned by the request, the son spent the next several days talking with physicians and others about the situation. He had not resolved how to deal with his father's request when the phone call came that his father had died during the night.

## CONCLUSION

The moral problems that Alzheimer's disease poses are as much problems of caregivers as they are problems of the afflicted. And those problems spread throughout the families of primary caregivers, throughout friendships, throughout business associates. These moral problems change with differing stages of the disease.

One of the important contributions of those of you who have professional roles of care have to make to families coping with dementia diseases is to help them cope with the range of moral issues they are facing and will face as the disease progresses. It helps to know that there will be problems of truth telling. It helps to be encouraged to accept the four As of acknowledgment, acceptance, affirmation and adjustment. It helps to be told of possible bizarre

behaviors, and to be encouraged to anticipate and plan for them. It helps enormously to be encouraged to join mutual support groups, where stories can be told and coping strategies shared and devised. I believe that openness, advance planning, encouragement of constructive family conferences, and periodic reviews with families of how the various participants are coping, are enormously important contributions that care givers can offer. The challenge, as with any stressful period in one's life, is to hold one's self together--to emerge with integrity, with the sense of what Nietzsche said: "That which does not destroy me makes me stronger."

And just to satisfy any lingering doubts, I am the son in the last story.

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James Lindemann Nelson and Hilde Lindemann Nelson, *Alzheimers* (New York: Doubleday, 1996).