



Alzheimer's: Ethical Questions and Answers from Diagnosis to Dying

By Stephen G. Post, PhD

Since 1990, Dr. Stephen G. Post has worked with deeply forgetful people and their caregivers across all 50 U.S. states and Canadian provinces through community dialogues, focus groups and ethics panels, organized in collaboration with local Alzheimer's Association chapters and coordinated through the national Association's policy division in Washington, DC.

As members of the healthcare community, we are all aware that Alzheimer's is a complex disease. Its diagnosis, treatment and prognosis vary with each individual who comes before us with a notebook full of questions that we cannot answer with any degree of certainty. The questions continue to come from the caregivers who are struggling to understand their undefined, confusing and often overwhelming role. Thrown into this mix is the physician's obligation to consider the disease from a bioethical standpoint.

Relying on the work of the Alzheimer's Association National Ethics Committee (on which this author served), this article seeks to give healthcare providers guidance on how to care for patients with Alzheimer's in an ethical manner, respecting patients' dignity, rights and wishes—even when they can no longer advocate for themselves.

ETHICALLY COMMUNICATING THE DIAGNOSIS OF DEMENTIA

Diagnostic truth telling in the context of dementia should be handled as it is in other medical contexts—be as truthful as information permits, while attending to the patient's need for social, emotional, spiritual and practical support. Compassionate diagnostic disclosure is a moral act of respect for persons, an opportunity to strengthen resilience and build community, and a necessary, practical step in planning for the future. Breaking the news supportively takes a lot of care and attention, but it can be done, with empathy—and some practice.

Although almost everyone agrees that compassionate honesty is the best policy, there are disagreements about the optimal kinds of emotional and relational support, about precise wording and timing, and about whether to inform the patient and the family or just the patient. When the diagnosis is Alzheimer's disease (AD), excuses for deception and nondisclosure are simply not valid. The most common excuses are anxiety, culture and lack of objectivity.

Anxiety. The idea of denying the truth to protect a patient from anxiety underestimates the remarkable human capacity to deal creatively and resiliently with the implications of serious diagnoses. (One exception is when addressing a patient with clinically significant depression, where a more cautious and gradual approach to disclosure is advisable.) In most cases, knowing about a diagnosis, and its emotional challenges for the patient, mobilizes family and community to provide the care and acceptance without which the patient will experience further isolation.

Culture. Physicians may encounter patients from cultures where nondisclosure to the patient is still the model, and families still operate in a highly protective manner. The physician will clearly want to take this into consideration as a matter of cultural sensitivity, but no physician should ever presume to withhold information, unless the patient

specifically requests that the physician do so.

Lack of objectivity. The syndrome called *dementia* is composed of a cluster of symptoms, but the core feature of dementia is a decline in cognitive abilities that causes significant dysfunction. Not presenting reasonably clear diagnostic information disenfranchises the person experiencing an illness—who usually is well aware of some losses—and creates a climate of distrust that will ultimately serve no good purpose.

As a result of this communication process, the affected person and the family should come to understand six facts:

- 1 The loss of memory is not normal, but results from changes in the brain.
- 2 Expectations for the future are uncertain, but in general, there will be further loss of memory.
- 3 Although the disease cannot be cured, many of its effects can be treated.
- 4 Having Alzheimer's does not mean that the patient cannot enjoy many experiences and retain his or her selfhood.
- 5 Support groups, such as those sponsored by the Alzheimer's Association, are available and effective.
- 6 The healthcare team will be available to provide assistance throughout the disease process, although the patient's quality of life will really depend almost entirely on nonmedical factors.¹

By informing the person of the diagnosis in a timely manner whenever possible, we enable him or her to prepare advance directives for healthcare decisions to be implemented upon eventual incompetence. An added advantage is that the person may be able to volunteer for certain types of Alzheimer's research. Most important, disclosure permits the person with dementia to participate in counseling and support group interventions, thus helping to alleviate anger, self-blame, fear and depression.²

TREATMENT WITH MEDICATION*

Researchers have found Alzheimer's one of the toughest diseases to decipher—and even tougher to treat. So, what are the ethics involved when a physician is asked, "What medicine can I take to treat this?" On a scale of 1 to 10, if insulin rates a 9 as an effective drug for treating diabetes, medications for Alzheimer's rate very roughly a 1. This is the cause of the dilemma.

Some doctors write prescriptions for the primary available Alzheimer's medications (acetylcholinesterase inhibitors or the N-methyl-D-aspartate [NMDA] receptor antagonist,

*Information in this section is provided with the assistance of Gregg Cantor, MD, Stony Brook University Medical Center.

memantine), but they are responding to the American tendency to place hope in magic bullets. Other doctors think that existing drug treatments are ineffective, at best. It is reasonable to give drugs a try, but it is also reasonable to avoid them or to stop taking them at some point because they have side effects and cost money, while providing few, if any, demonstrable benefits. The most common side effects of acetylcholinesterase inhibitors include insomnia, nausea, diarrhea, dizziness, falls and infection in more than 10 percent of those who take them. Memantine has been shown to cause dizziness, confusion, hallucinations, diarrhea, infection and urinary incontinence in 1 to 10 percent of patients.³

These medications can also impose a heavy financial burden on patients. Generic acetylcholinesterase inhibitors cost, on average, \$200 to \$250 per month, while memantine can cost an average of \$450 to \$500 per month.⁴

There is hope that sometime in the future an effective drug that slows or halts the progression of AD will be found. In the meantime, drugs to help with agitation, combativeness, hallucinations and aggression during the moderate stage of the disease are available. However, such problems often can—and ideally will—be managed by improvements in the patient’s environmental, communicative and social situation.

Decisions about the medications currently available to treat AD are ethically and financially complex. Their efficacy is limited, while the affected individual remains on the inevitable downward trajectory of irreversible progressive dementia. Nonchemical interventions focused on emotional, relational and spiritual well-being are often cheaper and more effective.

TREATMENT WITH CHEMICAL AND/OR PHYSICAL RESTRAINTS

The non-chemical interventions that offer sound alternatives to medication for patients with Alzheimer’s are often also better alternatives to the chemical and/or physical restraints used to manage behavioral problems. Social, environmental and activity modification, for example, are more desirable than physical restraints, which can result in unnecessary, and frequently hazardous, immobility; for example, people with dementia struggle for freedom and can harm themselves in the process. Strangulation, medical ailments caused by immobility and increased agitation are also among the serious and substantial harms caused by physical restraints.⁵

Using physical restraints out of concern for the safety of the person with dementia is a significant consideration, especially because for the frail elderly, falls can be very serious. But the potential harms of physical restraints must also be counted as risks to safety. Moreover, physical restraints increase the AD-affected person’s perception

of threat.⁶ Although safety is important, it does not justify involuntary restraint and the indignity of being tied down.

Health professionals need to be attentive to how family caregivers control the behavior of individuals with Alzheimer’s, and should encourage individualized and diverse approaches⁷ that do not resort to chemical and physical restraints.⁸ Consider wandering, for example. This behavior is seen in about half of people with dementia.⁹ Because of various side effects, there is no current drug therapy for wandering that will not also potentially interfere with other valued activities.⁷ Still, involuntary restraint is unethical and illegal.

As much as possible, people with dementia should remain free to wander in areas that are hazard-free and nonthreatening. Caregivers should view wandering as beneficial to the affected individual, and look for creative ways to allow it to occur in a safe, protective environment. They should register with the MedicAlert + Alzheimer’s Association Safe Return program (a nationwide registry of people with Alzheimer’s) to help first responders locate a lost individual.

Family caregivers may pressure physicians to “do something” quickly about behaviors that are offensive or frightening and cause emotional stress in the family. Society has come to expect prompt control of such behaviors, even if this requires resorting to chemical means. However, drugs to reduce disturbed behaviors (such as wandering, restlessness and irritability) create ethical issues when used at doses that interfere with a patient’s remaining cognitive function, and cause other side effects. If and when caregivers resort to behavior-controlling drugs, they should be used cautiously, and only for specified purposes. If psychoactive drugs are used, the purpose of treatment and the target symptom must be well defined; as few drugs as possible should be used, and they should be administered starting with low doses, increasing dosages slowly and monitoring carefully for side effects.¹⁰

Used sparingly in this context, drugs can have the desired therapeutic effects, help to maintain the home-care environment, lighten the burden on caregivers and make the use of physical restraints unnecessary. Thus, when used carefully to attain defined short-term goals, drugs can be highly beneficial,¹¹ making caregiving more manageable, without compromising the person’s quality of life.

ALLOWING A PEACEFUL DEATH

During the course of treatment, whether with medication, restraint or behavior modification strategies, it’s important to remember that deeply forgetful people are always present underneath the chaos or the silence, and they always possess consciousness as they take in the world around them. The fact that their rational processes are disordered or even absent is irrelevant with regard to the

respect they are owed as members of the human family. We need to keep in mind that they can have relatively good days, as well as bad ones, and that this is the only life they have.

The Alzheimer's Association concludes that Alzheimer's disease in *its advanced stage should be defined as a terminal disease*, as roughly delineated by such features as the inability to recognize loved ones, to communicate by speech, to ambulate or to maintain bowel and/or bladder control. When Alzheimer's progresses to this stage, swallowing difficulties and weight loss inevitably emerge. Death can be expected within a year or two, or even sooner, for most patients, regardless of medical efforts.¹²

One useful consequence of viewing the advanced stage as terminal is that family members will better appreciate the importance of palliative care (pain medication) as an alternative to medical treatments intended to extend the dying process.

Palliative Care. All efforts at life extension in this advanced stage create burdens and avoidable suffering for patients who could otherwise live out the remainder of their lives in greater comfort and peace. Cardiopulmonary resuscitation, dialysis, tube-feeding and all other invasive technologies should be avoided. The use of antibiotics usually does not prolong survival, and comfort can be maintained without antibiotic use in patients experiencing infections. Avoiding hospitalization will also decrease the number of persons with advanced Alzheimer's who receive tube-feeding because many long-term care facilities send residents to hospitals for tube placement, after which they return to the facility. In comparison with assisted oral feeding, however, long-term tube-feeding has no advantages and a number of disadvantages.¹³

Early discussions of a peaceful death should occur between persons with dementia and their families, guided by information from healthcare professionals on the relative benefits of a palliative care approach. Patients with advanced dementia experience symptoms that are responsive to palliative care, such as constipation and pain, yet healthcare workers often fail to treat these symptoms in a manner that provides relief. Instead, Mitchell and colleagues found that patients with dementia actually have more markers associated with poor quality of nursing home care, such as pressure ulcers, the use of restraints and the use of anti-psychotic medications, than do patients with cancer.¹⁴ It is possible that in patients with dementia, medication and restraints are used to control agitation that is actually a result of unmanaged pain.

Hospice Care. Patients with dementia also benefit from the palliative care provided by hospice programs, which are dramatically increasing their involvement with this population. Nineteen percent of individuals with dementia receive hospice care in a given year, a higher percentage

than for other chronic conditions.¹⁵ Dementia was the third most common primary diagnosis overall for Medicare beneficiaries admitted to hospice, with cancer the most common primary diagnosis.¹⁶ Additionally, those enrolled in hospice care are less likely to be hospitalized in the last 30 days of life¹⁷ and more likely to receive regular treatment for pain.¹⁸

Sadly, at the last assessment before death, only 50 percent of patients with dementia had an advance directive to limit invasive care, compared to 85 percent of patients with cancer. This discrepancy is reflected in the fact that two decades ago five times more patients with dementia than patients with cancer were subjected to an invasive treatment, such as tube-feeding, in part because professionals, the family and the person with Alzheimer's disease do not clearly acknowledge that AD is a terminal illness,¹⁹ and do not prepare advance directives. This is largely still the case.

PLANNING FOR A PEACEFUL DEATH WITH ADVANCE DIRECTIVES

When Alzheimer's has advanced to its late stages, it is impossible to ask the patient what he or she would like to do about treatment options. That is why early diagnostic truth-telling is the necessary starting point for an ethics of "precedent autonomy." This allows loved ones to make decisions for an incompetent person based on what that person desired before becoming incompetent. In the early stages of dementia, this can be done by completing advance directives such as a durable power of attorney for healthcare, coupled with a living will or some other specific indication of the patient's material wishes with regard to end-of-life care.

Unless the person knows the probable diagnosis in a timely way while still competent to file such legal instruments, however, the risk that he or she will be subjected to burdensome medical technologies is increased. Unfortunately, when many people reach the end of life, they have not prepared an advance directive; they have not created a durable power of attorney to deal with healthcare decisions, and their family members feel guilty if they don't summon all the marvels of modern medical technology to treat them. To ensure that individuals' wishes might be carried out in the final stages of the disease, preventing discomfort and a loss of dignity, patients with Alzheimer's need to do both—leave advance directives and assign someone durable power of attorney. This should make it unnecessary for those diagnosed with AD to later suffer a loss of dignity at the hands of technology.


In almost all cases, judgments of an individual's capacity to make medical decisions in a healthcare setting can be arrived at without the need for legal proceedings. In medical contexts, capacity, whether clinical or nonclinical,

includes the ability to understand relevant options and their consequences in light of one's own values. In the standard definition of a patient's capacity for medical treatment decision making in a living will with durable power of attorney, a patient must be able to do the following:

- 1 appreciate that he or she has a choice;
- 2 understand the medical situation and prognosis, the nature of the recommended care, the risks and benefits of each alternative and the likely consequences; and
- 3 maintain sufficient decisional stability over time, in contrast to the profound vacillation that indicates an absence of capacity.²⁰

It is important to plan for the global incompetency of advanced dementia through the use of advance directives: Estate wills, living wills and durable powers of attorney for healthcare decisions are necessary. The precedent self that is fully intact before the clinical manifestation of dementia has the legal right and authority to dictate levels of medical care for the severely demented self.

IN CONCLUSION

Nothing about Alzheimer's disease is easy. Not the diagnosis, not the treatment and certainly not the ethical obligations that healthcare providers owe to patients and caregivers. However, the guidelines established by the Alzheimer's Association National Ethics Committee make the task a bit easier, and more importantly, make it more likely that the dignity and the rights of our patients and their caregivers will be respected. 

Stephen G. Post, PhD, is the best-selling author of *Why Good Things Happen to Good People: How to Live a Longer, Happier, Healthier Life by the Simple Act of Giving*. His book *The Moral Challenge of Alzheimer's Disease: Ethical Issues from Diagnosis to Dying* was designated a "medical classic of the century" by the *British Medical Journal*. Post is one of three recipients of the Alzheimer's Association Distinguished Service Award.

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