# Empowering Patients with Alzheimer's Disease To Avoid Unwanted Medical Care: A Look At The Dementia Care Triad

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Wayne Shelton, PhD<sup>1</sup>, Evelyn Tenenbaum, JD<sup>2</sup>, Kevin Costello, MD<sup>3</sup>, and David Hoffman, DPS<sup>4</sup>

#### **Abstract**

Patients with Alzheimer's disease and other types of dementia with acute medical problems, who have lost capacity and are without advance directives, are at risk of being over treated inhospitals. To deal with this growing demographic and ethical crisis, patients with dementia need to plan for their future medical care while they have capacity to do so. This article will examine the role of each member of the dementia care triad and how to empower the patient to participate in planning future medical care. A case will be made that physicians have the same professional disclosure obligations to dementia patients as they do to all other capable patients with terminal illnesses. Because there is little consensus about what facts should be included in a diagnostic disclosure, this article will offer a proposal to empower newly diagnosed patients with dementia with capacity to plan for their future medical care.

#### **Keywords**

advance directives, capacity, dementia, dementia care triad

#### Introduction

Alzheimer's disease is a terminal neurodegenerative disease for which there is currently no effective treatment to abate its progression. Persons with Alzheimer's, depending on their age, typically live only 3 to 10 years after diagnosis, yet some may live longer with Alzheimer's dementia. Currently, persons with dementia are 3 times more likely to be hospitalized than patients without dementia and often need long-term care. Upon entering the acute care system, patients who have lost decisional capacity and lack clear advance directives are more likely to receive unwanted life-prolonging interventions that may increase suffering and provide few, if any, benefits. By contrast, persons with cognitive impairments who expressed their prior wishes in an advanced directive receive significantly less aggressive treatments at the end of life compared to similar persons without them.

To deal with this growing demographic and ethical crisis, persons with dementia need to plan for their future medical care while they have capacity to do so. Most persons with dementia and caregivers want candid information about what the future holds for them, but that information is not provided in nearly half of all cases in which patients still have capacity. This is in part because many physicians are uncomfortable having the conversation or are uncertain about whether anything constructive can be accomplished. The result is that too often capable persons with dementia who receive some information about Alzheimer's disease or other dementias are often not given a

full disclosure of their diagnosis and prognosis that would allow them to competently complete an advance directive and plan for an uncertain future. The is difficult to avoid the conclusion that the physician—patient—caregiver triad, or the dementia care triad, is not working nearly as well as it could. Because of the conclusion of t

This paper will examine the role of each member of the dementia care triad and highlight the obligation of the health-care provider to disclose the dementia and possible Alzheimer's disease diagnosis so as to empower the patient to participate in planning future medical care. The barriers, real or perceived, to physicians fulfilling this obligation will be addressed. A case will be made that physicians have the same professional disclosure obligations to their patients with dementia as they do to all other capable patients with terminal illnesses. Because there is little consensus about what facts should be included in a diagnostic disclosure, this paper will offer a proposal to empower newly diagnosed persons

#### **Corresponding Author:**

Wayne Shelton, PhD, Department of Medicine, Alden March Bioethics Institute, Albany Medical College, 47 New Scotland Avenue, Albany, NY 12208, USA.

Email: sheltow@mail.amc.edu

<sup>&</sup>lt;sup>1</sup> Alden March Bioethics Institute, Albany Medical College, Albany, NY, USA

<sup>&</sup>lt;sup>2</sup> Albany Law School, Alden March Bioethics Institute, Albany, NY, USA

<sup>&</sup>lt;sup>3</sup> Department of Medicine, Albany Medical College, Albany, NY, USA

<sup>&</sup>lt;sup>4</sup>New York State Department of Health, Albany, NY, USA

with dementia and with capacity to plan for their future medical care.

# The Dementia Care Triad: The Foundation of Support

The dementia care triad—the patients with dementia's basic support system includes the patient, the caregiver of the patient, and a medical professional, usually a physician or other provider from whom the patient receives primary care.<sup>8</sup>

#### **Patients**

People with Alzheimer's disease and other types of dementia, like all others, have the right to receive person-centered medical care. Though persons with Alzheimer's and other dementias are at considerable risk of losing capacity, that is, the ability to make their health-care decisions independently, many retain capacity in the early to moderate stages of their disease and have a right to participate fully in their medical care planning within the triad. Even in moderate or later stages, persons "with obviously impaired capacity may still be able to indicate a choice and show some understanding," which may become ethically relevant especially when they are resisting a burdensome treatment with limited efficacy.

Persons with Alzheimer's and other dementias with capacity may prefer to complete advance directives on their own. Others may seek help understanding the implications of the disease and obtain decision-making support from the physician and the caregiver or surrogate. Still others, for personal or cultural reasons, may defer receipt of disclosure and decision-making to another individual. Newly diagnosed persons with Alzheimer's and other dementias may feel frightened, depressed, distraught, or, in rare cases, suicidal. Optimal support to these individuals would allow them to explore and process those feelings and concerns.

If they are to be empowered, both the person with dementia and his or her surrogate need to know that their enduring self-awareness and current, conscious life, including commitments, beliefs, relationships, work, and so on, will fade as dementia progresses. However, even after losing decisional capacity, the person will continue to express natural, experiential interests in food, social interaction, sex, music, and so on, for an indefinite period. This will provide some basis for quality of life even in advanced dementia. Understanding the transition from the former self, with continuous, coherent interests, to the self in advanced stages of dementia—what we might call the "now" self—with fleeting, experiential interests, will provide an important context for making well-informed decisions regarding life-prolonging treatment.<sup>14</sup>

# Caregivers

Caregivers for persons with Alzheimer's and other dementias may be anyone with a close relationship to the patient. They are individuals who genuinely care about the person for whom they are caring and are willing to dedicate time to helping the patient with activities of daily living, from the time the person is relatively independent to the time when he or she may be completely dependent on others. Most caregivers for persons with dementia, about two-thirds, are female family members, who bear considerable emotional, physical, financial, and opportunity costs for the sake of the patients they serve. <sup>15</sup> At the same time, in the right circumstances, the caregiving role can be a source of satisfaction and personal fulfillment. <sup>16</sup>

Caregiver stress in dementia has been shown to be influenced by assumptions and beliefs about the caregiving role and understanding of the course of the underlying disease in the progression of symptoms.<sup>17</sup> If a caregiver does not understand the progressive nature of Alzheimer's disease and other dementias, she may believe that the patient's inevitable decline is a consequence of her own shortcomings as a caregiver despite exhaustive efforts, leading to feelings of guilt and frustration.<sup>18</sup> Such frustration may lead to redoubling of efforts to control patient behavior in ways that paradoxically worsen the situation for the entire triad.

Since the primary caregiver often has the closest relationship with the person with Alzheimer's or other dementias, that caregiver is often, but not always, the one appointed by the person with dementia to serve as agent or surrogate healthcare decision maker in anticipation of losing capacity. This responsibility requires the individual to process complex medical information about the patient's condition and understand the patient's preferences and goals for medical care, so she or he can make medical decisions in accordance with the patient's wishes as much as possible. 19 Advance directives have helped surrogates make decisions using substituted judgment and thus are an important part of the process.<sup>20</sup> Though it will be impossible to precisely predict the future medical decisions that need to be made in every situation, advance directives still provide essential and useful guidance for a surrogate giving voice to the patient's preferences and priorities.

Surrogates must deal with their own emotional reactions, such as grief and loss and not let those reactions cloud their sense of what is in the best interest of the patient. The emotional and physical well-being of caregivers is also at risk and so they must also receive the support and care of the health-care workers who are caring for the patient. 8

## Primary Care Physicians

Primary care physicians have a key role in determining the quality of care that a newly diagnosed person with dementia will receive, as they are often the first point of contact with the health-care system for patients exhibiting new signs and symptoms consistent with dementia. When the primary care physician makes a diagnosis of dementia or likely Alzheimer's disease, it is his or her responsibility to assess the patient's decisional capacity. Assessing capacity in newly diagnosed persons with Alzheimer's disease and other dementias can be challenging, and the determination of capacity may be uncertain; a meaningful discussion of the patient's diagnosis and

Shelton et al

prognosis in such instances may be not be possible. But in those situations where capacity is evident to the primary care physician, the discussion should take advantage of this window of opportunity. The provider must thoughtfully disclose the diagnosis after exploring the patient's preferences and vulnerabilities, including insight and supports for receiving, understanding, and responding to potentially devastating news. 9

Once the patient and/or surrogate are capable, intellectually and emotionally, of comprehending and accepting this new context, the triad should begin the discussion about advance directives that will culminate in a plan for future medical care, particularly with respect to invasive life-prolonging options such as CPR and intubation when the patient reaches advanced stages of dementia. There is evidence that often this discussion does not happen. Consequently, many persons with Alzheimer's and other dementias with capacity lose their opportunity to fully understand their diagnosis and engage in conversations about future medical care planning and are left at great risk of receiving inappropriate, burdensome medical care.

# **Getting Beyond Barriers To Full Disclosure**

There are real and perceived barriers to physicians engaging patients and their caregivers struggling with Alzheimer's disease and other dementias in the very necessary process of disclosure, education, and medical care planning described above. We will examine 3 main ones.

## Lack of Time

Lack of time is perhaps the most common barrier physicians cite as a reason for not getting into extended conversations with patients and caregivers about the complexities involved in advance care planning.<sup>23</sup> There is no question that these conversations require ample time free of distractions, a real problem for busy physicians with a full schedule of patients and strict time limits allocated for each visit. Ideally, the opportunity for patients and professional caregivers should be built into all health-care systems so that physicians would be reimbursed for their time.<sup>24</sup> The recent ruling by the Center for Medicare and Medicaid Services in the United States to reimburse physicians for having advance care planning conversations with patients should improve this situation at least somewhat, hopefully alleviating previous financial constraints.<sup>25</sup> Factors other than economic considerations, to the extent that they contribute to time constraints, should also be explored and addressed. For example, if the need for such a discussion is identified, but the schedule does not permit time for the discussion during the current encounter, more time might be allotted for a longer encounter on a subsequent follow-up visit. This would enable the provider to address the usual follow-up of comorbid issues and still leave time to engage in advance care planning. The time between the 2 encounters can be an opportunity for the patient and surrogate to frame their thoughts and questions for the next meeting about the disease and advance care planning. Moreover, physicians can further save time by fully utilizing nurses, medical social workers, case managers, and other team members, to give the patient and caregiver the information they need to complete an advance directive.

# Lack of Comfort and Knowledge

Another barrier is physicians' lack of comfort and knowledge about counseling persons with Alzheimer's and other dementias. In a recent survey of over 700 primary care and specialist physicians in all 50 states, almost half reported they often or sometimes felt unsure of what to say in end-of-life conversations. These difficult discussions require that physicians assess the patient's capacity, explain advance directives and viable ways to think about future medical care, and effectively respond to the natural reactions of grief, doubt, and stress in the face of uncertainty. And stress in the face of uncertainty. Not surprisingly, there is evidence that physicians with training in how to have these conversations do so with greater comfort.

For those still working to acquire the needed skills and confidence, community-based resources—such as the local municipal or county office for aging or a local chapter of the Alzheimer's Association—medical social workers, geriatric care managers, or clergy can be helpful partners in the discussion.

Just as patients cannot make good informed advance care decisions without full understanding of their diagnosis and prognosis, primary care physicians may not be motivated to foster and lead the advance care planning discussion if they do not appreciate, through experience or otherwise, the downstream harms of delaying advance care discussions beyond the window of patient decisional capacity. Physicians must realize that failure to have these discussions robs the patient of autonomy and later places perceived and real clinical and moral burdens on themselves and on surrogates. The need to make substituted judgments opens the door to false choices regarding interventions of little or no benefit, leaving the patient exposed to increased risk of receiving undesired aggressive medical treatment. When the patient's wishes are clearly expressed in an advance directive the primary care physician should keep a copy in the patient's medical record and available for future use as the patient's disease progresses.

# Fear of Overwhelming the Patient With Bad News

The third barrier to be considered is the fear of overwhelming the patient and caregiver with bad news, which may be particularly serious in settings with inadequate provision of palliative care services. <sup>24</sup> The dementia diagnosis comes with dire lifechanging expectations, including loss of independence, caregiving needs and expenses and perhaps the dashing of one's late life goals. However, there are far greater risks of harm if the patient remains in the dark and cannot adequately plan for the future. Moreover, interview studies have revealed that most patients favor full disclosure of a dementia diagnosis, <sup>29,30</sup> and beyond that, patients and caregivers want more information following disclosure. <sup>31,32</sup>

However, neither brutal honesty nor sugar-coated euphemisms are viable options. Rather, disclosure should be a gentle unfolding of a planned process in which the caregiver and the primary care provider assure each other and the patient of continuous presence and support in the difficult times to come. The greatest relief for the patient does not come from information being withheld, even with the best of intentions, but from being given every opportunity to retain control of her or his life while capacity to do so remains and knowing that a surrogate of her or his choosing will be a faithful representative when that time has passed.

Sensitive but honest truth-telling is more likely to occur if the provider employs an interactive, rather than didactic, approach. By giving the other 2 members of the triad a safe space to ask questions, receive desired information, examine options, and express values and preferences, the provider is given the opportunity to listen, observe reactions and thought processes and be in a better position to identify and dispel misunderstandings, unfounded fears, and unrealistic expectations, good or bad.

In summary, though the barriers cited above cannot be taken lightly, each can be managed and overcome so patients and their caregivers are given the quality care they deserve.

# A Proposal for Full Diagnostic Disclosure of Alzheimer's

In spite of physicians' track record for not providing disclosure to newly diagnosed persons with Alzheimer's disease or other dementias, there is near universal agreement, including from physicians, that they should do so.<sup>33</sup> However, there are few specifics in the literature as to what the disclosure should include, particularly in describing the prognosis. A crucially important question becomes, what counts as sufficient information in a diagnostic disclosure and conversation about the disease?

As a representative example, the Alzheimer's Association recommends covering the following key issues about the nature of the Alzheimer's disease: (1) Alzheimer's disease is not a normal part of aging but a degenerative disease of the brain that results in impaired memory, thinking and behavior. (2) Alzheimer's disease affects every individual differently, so there is no exact way to determine how the disease will progress. (3) Although there is no cure for the disease, some of its symptoms can be treated by medications and behavioral approaches. <sup>1</sup>

Clearly it would represent considerable progress if all newly diagnosed patients with capacity received this information from their physician. However, given that patients and their caregivers want more information, not less, and there is so much at stake in terms of the patient's future quality of life which requires careful planning, we propose the following more explicit information be made available to newly diagnosed persons with Alzheimer's and other dementia:<sup>34</sup>

- Alzheimer's disease and most other dementias are terminal illnesses for which there are currently no curative treatments
- The person will continue to decline in cognitive function, unless succumbing to another more life-limiting condition first.
- Dementia complicates the management of comorbid conditions and raises contextual questions about how to balance the harms versus benefits of future medical treatments<sup>35,36</sup>
- The person will require increasing levels of care and support and will eventually become totally dependent on others.
- However, the person will continue to have many interests, such as social interaction, music, outdoors, and more, that can be a source of comfort and maximum comfort care is available.
- 6. The more the person is able to clearly state his or her wishes and goals for future health care in an advance directive, the more likely it is that health care will be provided in accordance with those wishes. Without such planning, they will likely be at considerable risk of being treated with default aggressive medical treatment, much of which may be burdensome and nonbeneficial.<sup>18,37-39</sup>

Physicians should see disclosure as a process throughout which they will provide reassurance and a commitment to be available for ongoing support. We realize this is a lot of information for a stressed patient and caregiver to digest and it is seldom advisable to cover it all in one session. But there is reason to believe that when patients know their diagnosis and the types of medical interventions possible when the disease moves to advanced stages, most of them will want comfort care to be the primary goal. Without full disclosure, patients may receive care that is contrary to their wishes and values.

The knowledge and skills necessary for a physician to provide a clinically artful disclosure of diagnosis and to lead a discussion of future medical care should be considered as much a core competency as possessing basic medical knowledge and being able to perform procedures. A shift to ensure that dementia patients receive adequate information about their disease would be a paradigm shift similar to what happened in the care of patients with cancer from 1960 to 1979, when physicians changed their habits from concealing the diagnosis in most cases to almost always providing full disclosure. With respect to Alzheimer's, there is some evidence that such a shift has begun, but disclosure will not be fully implemented without the development and dissemination of a systematic approach for primary care physicians and other health professionals to use when confronting these diseases.

Organizations like the American Geriatrics Society, the Alzheimer's Association, and Health Resources and Services Administration have produced high-quality educational resources for medical professionals, as well as for patients and caregivers to support the discussion of advance directives. 43,44

Shelton et al 135

# **Conclusion**

We have reached the point at which providing full disclosure to patients with Alzheimer's disease and other types of dementia is a fundamental physician obligation. If capable patients do not receive full disclosure, the dementia care triad is weakened and patients are left in jeopardy of being treated with burdensome and unnecessary interventions, which may cause needless suffering.

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