



Markkula Center

for Applied Ethics

at Santa Clara University

ETHICAL CONSIDERATIONS FOR END-OF-LIFE CARE WITH ALZHEIMER'S DISEASE

AN EXPLORATORY PROJECT IN HEALTH CARE ETHICS

What ethical issues arise when terminal neurological diseases, such as Alzheimer's prevent individuals from making medical decisions?

THE ALZHEIMER'S-SPECIFIC ADVANCE PLAN (ASAP)

A modified advance directive that facilitates conversations and documentation of an individual's wishes while they are healthy

A way to attend to feelings of fear or anxiety about future loss of independence

Standard advance directives are not specific enough to be a useful tool for individuals with Alzheimer's Disease and their surrogate decision-makers

MORE THAN A STANDARD ADVANCE DIRECTIVE

Content by
Honzel Fellow, Miyuki Dougherty '18
Markkula Center for Applied Ethics
scu.edu/ethics

ETHICAL CONSIDERATIONS FOR END-OF-LIFE PLANNING WITH ALZHEIMER'S DISEASE

PART I: ALZHEIMER'S DISEASE

A progressive, degenerative neurological disease caused by nerve cell death and tissue loss in the brain. Alzheimer's damages brain regions responsible for planning, remembering, language processing, and motor control

Alzheimer's is incurable and terminal, though disease progression varies greatly -- individuals can live 4 - 20 years after diagnosis, or 8 years on average

STAGES OF ALZHEIMER'S DISEASE

EARLY STAGE

Mean duration: 2 years

Individuals can still function independently, work, engage in social activities, drive, and take care of oneself

Occasional memory lapses -- e.g. problems coming up with the right word or name, trouble remembering names when meeting new people, decrease in organizational skills

MODERATE STAGE

Mean duration: 6 years

More obvious symptoms require more attention and care from others

Increasing trouble keeping words and phrases in line, frustration and anger, unexpected behaviors -- e.g. refusing to dress or bathe

ADVANCED STAGE

Mean duration: 5 - 6 years

Significant memory loss and cognitive impairment -- changes in physical abilities, increasing difficulty communicating, increased risk of infections such as pneumonia

Individuals lose significant ability to engage in basic activities of daily life -- e.g. speech is limited to a few intelligible words per day, inability to sit up independently

END STAGE

Mean duration: 1 - 2 years

Characteristic terminal phase during which Advanced Stage symptoms worsen

Increasingly severe decline in functional status -- e.g. smiling reduced to grimacing facial movements, difficulty holding head up independently, physical rigidity leading to contractures, neurological reflex changes, difficulty eating and swallowing, full-time help with personal care, high susceptibility to infections

MEDICAL DECISION-MAKING CAPACITY THROUGH ALZHEIMER'S

In order to make medical decisions for oneself, an individual must possess medical decision-making capacity, as assessed by a physician



As cognitive function progressively declines, individuals lose the mental capacity to make medical decisions for themselves.

Medical decision-making capacity requires that upon the opportunity to choose/refuse a particular type of care an individual can:

- 1) *Make and communicate a clear choice* (e.g. *I want this back surgery because I am in pain*)
- 2) *Understand the information relevant to such choice* (e.g. *I understand why I am getting this surgery, etc.*)
- 3) *Evaluate treatment options, including doing nothing, and their potential consequences* (e.g. *If I get the surgery, there is some risk and pain involved. If I do not get the surgery, my pain may worsen and I may need more serious treatment later, etc.*), and
- 4) *Reason rationally* (e.g. *to weigh risks and benefits of each option*)

The distinction between **capacity** (*medical determination*, via a physician) and **competency** (*legal determination*, via a judge) is crucial in medical decision making, as these terms are often used interchangeably. We are concerned with **capacity**, as it refers to the **ability to make specific types of medical decisions**.

ETHICAL QUESTIONS TO CONSIDER:

- 1) *Who ought to make medical decisions for patients who can no longer decide for themselves due to Alzheimer's Disease?*
- 2) *Given the extended time frame of the progression of Alzheimer's Disease, and that patients lose their decision-making capacity, how can we honor patients' wishes in a health care environment that relies on autonomy and real-time decision making?*

ETHICAL CONSIDERATIONS FOR END-OF-LIFE PLANNING WITH ALZHEIMER'S DISEASE

PART II: ADVANCE CARE PLANNING WITH ALZHEIMER'S

Implications of Alzheimer's Disease Progression for Advance Care Planning (ACP)

Alzheimer's is a terminal disease that first affects the parts of the brain associated with learning, but then progresses, leading to more severe symptoms that affect the whole body (e.g. disorientation, mood and behavior changes, more serious memory loss, difficulty speaking, difficulty swallowing, and difficulty walking and sitting up.)

It is not possible to accurately estimate life expectancy upon diagnosis with Alzheimer's – on average, individuals live 4 – 8 years after an Alzheimer's diagnosis, though survival can range from 4 to 20 years after diagnosis depending on an individual's age and other health conditions.

ADVANCE CARE PLANNING AND ADVANCE DIRECTIVES

Advance Care Planning (ACP) involves discussing an individual's preferences for medical care that they would like to receive at a time when they cannot make such decisions or cannot communicate such decisions. "The goal is to try to more proactively make decisions and understand patients' values rather than just reacting to changes in condition." – Dr. Kathleen Tschantz Unroe, MD, Indiana University Center for Aging Research

According to Charles Sabatino, JD, Director, Commission on Law and Aging at the American Bar Association (ABA) there are **two overriding goals for Advance Care Planning (ACP)**:

- (1) *To establish a surrogate decision maker (a legal activity)*
- (2) *To express an individual's values, treatment goals, and wishes (a communication task)*

Evidence-based care guidelines from the **Alzheimer's Association's** quality of care campaign recommends having **ACP conversations** in the **early stage of Alzheimer's Disease**, when an individual's cognitive and communication abilities are least impaired. This allows surrogate decision makers to have a clear understanding of a patient's values and preferences for future medical decisions.

*These conversations can be documented in an **Advance Directive**.*

Types of directives include:

- **Living will** – one can define treatments he/she wants to receive/refuse -- e.g. cardiopulmonary resuscitation (CPR), extended care on a breathing machine, tests, medications, surgeries, artificial nutrition and hydration
- **Medical power of attorney** – a legal document naming another person to make proxy health care decisions; A.K.A health care proxy, agent, or surrogate decision maker
- **Physician/Medical Order for Life-Sustaining Treatment (POLST/MOLST, etc.)** – a medical order for specific medical treatments during a medical emergency, *only appropriate for individuals with a serious illness or advanced frailty near the end of life*

According to a meta-analysis conducted in 2017, only about 37% of U.S. adults have completed an Advance Directive.



The progressive cognitive decline that is characteristic of Alzheimer's poses significant challenges to completing an Advance Directive, rendering it impossible once the patient loses the capacity to decide.

STRENGTHS AND WEAKNESSES OF STANDARD ADVANCE DIRECTIVES WITH

STRENGTHS

ALZHEIMER'S

WEAKNESSES

- Comprehensive ACP and Advance Directives can allow family members and caretakers to make medical decisions that **honor the patient's wishes** when he/she loses capacity
- Advance Directives that are incorporated into comprehensive goals-of-care discussions may help **reduce surrogate decision-maker stress** associated with making proxy medical decisions

- **Standard ACP and Advance Directives** are generally not helpful for individuals with dementia (Alzheimer's is the most common form of dementia), whose *needs may change as the disease progresses*
- The December 2017 issue of the *Journal of the American Medical Association (JAMA)* points out that **dementia is a "unique disease from the standpoint of advance directives..."**

ETHICAL CONSIDERATIONS FOR END-OF-LIFE PLANNING WITH ALZHEIMER'S DISEASE

PART II - CONTINUED

STRENGTHS AND WEAKNESSES OF STANDARD ADVANCE DIRECTIVES WITH ALZHEIMER'S (CONTINUED)

STRENGTHS

- o This is important because these conversations can help **fulfill end-of-life care wishes** and clarify an individual's wishes

However, standard Advance Directives do not allow individuals to create dynamic, specific instructions for future medical decisions as their goals of care change throughout the disease's progression

WEAKNESSES

- ... It usually progresses slowly over many years and leaves people with a long time frame of diminishing cognitive function and loss of ability to guide their own care."
- Existing Advance Directives "typically address scenarios such as imminently terminal condition or a permanent coma, but they generally do not address the more common scenario of gradually progressive dementia" making them **less helpful** in the context of **loss of cognitive function that occurs over an extended time-frame**

ALZHEIMER'S IN THE ABSENCE OF ADVANCE CARE PLANNING

- Without access to or knowledge of Advance Care Planning and Advance Directives, medical decisions for individuals with dementia are likely to fall on surrogate decision makers, usually family and/or caregivers
 - o Family members/caregivers frequently struggle with trying to guess their loved ones wishes -- e.g. when to transition between levels of care such as hospitalization, full treatment, do-not-resuscitate (DNR) orders, home care only, and comfort care measures only
- When clinicians and surrogate decision makers are unsure of a patient's goals of care, they may not know how they should adjust the intensity of the patient's treatment and "often find it easier to continue treatment paths rather than having conversations about whether such care is what a person with dementia would have wanted," e.g., heart failure, treatment options such as a pacemaker, surgery, etc.

This is a critical issue for ACP in general, but especially so when ACP addresses progressive neurodegenerative diseases such as Alzheimer's, as loss of cognition can impact the suitability of various treatment options.

"The default in our medical system is aggressive care unless there is a clearly written, in-your face, advance directive...that is the American culture and the American medical culture."

- Dr. Unroe

ACP is also extremely important if a patient does not want aggressive treatment.

ETHICAL QUESTIONS TO CONSIDER:

1) ACP is very important for Alzheimer's patients and should be done as early as possible after diagnosis. Should insurance companies/Medicare require individuals diagnosed with Alzheimer's to complete an Advance Directive if they have decision-making capacity? Should insurance companies/Medicare pay for costs associated with completing an Advance Directive?

2) Are there types of decisions that would be inappropriate to make at an early stage of the disease?

3) In the absence of a clear indication of patient wishes regarding future care, are there treatment options that ought to be reconsidered by the surrogate decision maker in light of Alzheimer's?

4) Should an Alzheimer's patient's right to decide be honored when the decision has been made years, perhaps, decades before?

5) How can we approach the issue of an Alzheimer's patient's "then-self" and "now-self" when his/her expressed wishes when now incapacitated do not align with an existing advance directive? Ought we to follow an advance directive that a person who has lost decision-making capacity now refutes?

6) Should we withhold nutrition and hydration as indicated on an advance directive even though the now incapacitated patient expresses a desire to eat and drink and appears to experience pleasure when being fed?

ETHICAL CONSIDERATIONS FOR END-OF-LIFE PLANNING WITH ALZHEIMER'S DISEASE

PART III: THE ALZHEIMER'S-SPECIFIC ADVANCE PLAN (ASAP)

Ethical mandate: The loss of cognitive function ought never to be a reason to provide or endure substandard decision making and medical care, especially at the end of life.

In efforts to achieve concordance between a patient's informed goals and medical care Gaster *et. al*/ developed a dementia-specific directive that, if implemented, "could improve care for patients with dementia by promoting more thoughtful, compassionate approaches to care in the later stages of the disease."

What is a dementia-specific directive?

A dementia-specific directive is a document that allows individuals with dementia to communicate their goals for future medical care (cite). This document divides the milestones of dementia-associated cognitive decline into stages (mild, moderate, and severe) and provides a general description of what one may expect to experience at each stage.

The dementia-specific directive is **not** intended to be a **legally binding document**, but rather to serve "as a communication tool to allow a patient...to express what their values and goals of care would be for the future" and to **supplement** a legal document such as an **Advance Directive**. The dementia-specific directive should be implemented as a **series of conversations** that provides a clarity of wishes between the patient, neurologist, and primary care physician.

Benefits of a dementia-specific directive



The dementia-specific directive provides more specificity in the context of dementia. One may argue that we may be unable to accurately imagine our sense of autonomy and quality of life in some medical circumstances such as stroke or paraplegia, but that we are capable of envisioning our future when we lose our sense of self.

Moving forward with the dementia-specific directive

We ought to apply this dementia-specific directive to individuals diagnosed with Alzheimer's (the most common form of dementia) because this document **will enable informed individual decisions to be carried forward, without relying on interpretations by a surrogate decision-maker.**

This directive allows us to consider the trajectory of dementia and its multiple conditions, and create a subsequent set of wishes.

Although this new directive can be used for dementia in general, we should consider creating an even more specific ACP tool for individuals diagnosed with the most common form of dementia, Alzheimer's Disease. This Alzheimer's-Specific Advance Plan (ASAP) not only accounts for the three general stages of dementia (i.e., mild, moderate, severe) but also for the specific attributes and challenges of end-stage Alzheimer's. **Alzheimer's-Specific Advance Plan (ASAP).**

ALZHEIMER'S-SPECIFIC ADVANCE PLAN (ASAP)

Because patient goals of care are likely to change as the disease progresses, ACP ought to include consideration of an Alzheimer's Specific Advance Plan (ASAP) *in addition* to the standard Advance Directive for all individuals diagnosed with Alzheimer's. One may argue that we should not make medical decisions for ourselves years in advance because we cannot accurately imagine our long-term quality of life in the wake of a debilitating circumstances and how our future self would respond. We do not know how our outlook on life will change as time passes.

However, we are capable of envisioning our future with Alzheimer's disease because the trajectory of the disease progression is predictable and well-known. Perhaps this is why ACP is so important for Alzheimer's patients-- **we are capable of envisioning a future in which we lose our sense of self, when we no longer take interest in the passions that define us, when we no longer recognize the people we love, and when we fail to comprehend our own reality.**

The ASAP and dementia-specific directive have **very similar goals** of discovering and documenting patient values and desires in that:

- 1) The ASAP allows individuals with Alzheimer's to outline their goals of care ahead of time based on the cognitive milestones of the disease
- 2) The ASAP is not legally binding, and *will work in conjunction with an Advance Directive* and information provided by family and friends to provide **additional goal-oriented specificity** to those responsible for medical decision making including at the end of life

ETHICAL CONSIDERATIONS FOR END-OF-LIFE PLANNING WITH ALZHEIMER'S DISEASE

PART III - CONTINUED

However, the ASAP is different from the dementia-specific directive in that:

- 1) *It accounts for the identifiable clinical end stage of Alzheimer's that is not adequately addressed by the dementia-specific directive in its current form*
- 2) The ASAP acronym emphasizes that ACP conversations and documentation should be implemented upon diagnosis with Alzheimer's, and reminds clinicians that such conversations with patients and their families **cannot wait, at least not for long**
- 3) It allows patients to express explicit wishes for their care as their disease progresses
- 4) It highlights that ACP ought to grant dignity and extended autonomy to guide medical care to *all individuals*, regardless of whether cognitive function is retained or lost as health declines

The Alzheimer's-Specific Advance Plan (ASAP) applies to:

- Any individual with a diagnosis of Alzheimer's disease who at the time conversations are had, choices are considered, and the form is signed possesses medical decision-making capacity

The ASAP attempts to improve the quality of medical care for persons with Alzheimer's disease by:

- Prompting earlier conversations about medical care after a diagnosis of Alzheimer's Disease
- Discussing and documenting specific preferences for future treatment at various stages of Alzheimer's at a time when the patient possesses medical decision-making capacity
- Alleviating the surrogate decision maker's stress and the burden commonly associated with making proxy medical decisions for a loved one with Alzheimer's
- Recognizing an individual's autonomy in defining his/her own quality of life and outlining stage-specific goals to guide medical care when capacity is inevitably lost

These features of the ASAP illuminate one of the most compelling reasons for the ASAP -- its *simultaneous* **extension of patient autonomy and protection against any treatment that is inconsistent with patient values and desires** -- especially when the patient's ability to communicate is diminished or absent. The ASAP may also **prevent inadvertent undertreatment or overtreatment** by physicians and/or well-meaning family members and surrogates.

For practical and widespread adoption, the ASAP should be brief and accessible, but detailed enough to address:

- (1) The changes in cognition that occur as Alzheimer's progresses
- (2) The changes in goals of care along the continuum of the disease
- (3) Treatment options explicitly keyed to each stage of the disease

To implement the ASAP*:

1) A primary care physician (PCP) or neurologist assigns each newly diagnosed individual and their family/friends/caregivers an **Alzheimer's Advocate**, similar to an oncology **Patient Navigator**, preferably at the time of diagnosis or within a couple weeks thereafter. The meeting with the Alzheimer's Advocate may take place immediately or after the patient and family have had time to consider this new reality

2) Alzheimer's Advocates provide individuals with the necessary information and documentation to create a standard **Advance Directive** in conversation with his/her family members if the patient has the capacity to do so

3) After the Advance Directive is completed, the Alzheimer's Advocate will organize a follow-up appointment with the patient, his/her family members, the designated surrogate decision maker, and caregivers to discuss the Advance Directive and to **introduce and discuss an ASAP** (in addition to other end-of-life planning options), preferably within a month after diagnosis

a. *The most important part of the ASAP is the **conversation** among patients, family, surrogate, caregivers, and, if possible, clinicians. These conversations help familiarize all individuals with the patient's values, "allowing for consistent recommendations and concordant care." Completing an Advance Directive and ASAP is a method of **documenting** such conversations, which can be used in the future to remember the values and desires expressed and the decisions that were made*

b. *Each individual and his/her family may react differently to an Alzheimer's diagnosis. For this reason, the Alzheimer's Advocate will facilitate this conversation either:*

ETHICAL CONSIDERATIONS FOR END-OF-LIFE PLANNING WITH ALZHEIMER'S DISEASE

PART III - CONTINUED

- i. Upon diagnosis with Alzheimer's – if the individual is ready to communicate and document their values and wishes for future medical care; or,*
- ii. Within a few weeks of diagnosis with Alzheimer's – to ensure that individuals complete their ACP in a timely manner, and to ensure that an individual has enough time to consider their values and wishes for future care as the disease progresses*

4) Once these documents are completed, copies should be given to the designated surrogate decision maker and to the patient's physician(s) to be included in the patient's medical record

5) Future medical care should follow the wishes and guidelines outlined by the patient. Most importantly, medical care should follow the patient's values and wishes expressed during ACP, which is documented in the Advance Directive, ASAP, and, when appropriate, a POLST or equivalent.

** Only individuals who still possess medical decision-making capacity are qualified to create an Advance Directive and an ASAP for future medical care. If an individual does not have the capacity to create an Advance Directive, efforts should still be made to complete a Values Survey or a documented conversation with the individual about what is important to them.*

THE ASAP AS MODIFIED FROM THE 2017 JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION'S DEMENTIA-SPECIFIC DIRECTIVE

Please complete the following sentences:

"If I had (mild, moderate, advanced, or end-stage Alzheimer's, then I would want the goal for my care to be":

1) To live for as long as I could. I would want full efforts to prolong my life including efforts to restart my heart if it stops beating at this stage:

- a. Early*
- b. Moderate*
- c. Advanced*
- d. End-stage*

2) To receive treatments to prolong my life, but if my heart stops beating or I can't breathe on my own, then I would not want my heart shocked and I would not want to be placed on a breathing machine. Instead, allow me to die peacefully. I choose this option, at this stage, because if I took such a sudden turn for the worse, my dementia likely would be worse if I survived, and I would not want the trauma of cardiopulmonary resuscitation or a breathing machine.

- a. Early*
- b. Moderate*
- c. Advanced*
- d. End-stage*

3) To receive care only in the place where I am living. I would not want to go to the hospital even if I were very ill. If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such treatment. But if I continued to get worse and treatment could not be provided where I am living, I would not want to go to a hospital. Instead, I would want to be allowed to die peacefully at home. I choose this option, at this stage, because I would not want the possible risks and trauma that can come from being in the hospital.

- a. Moderate*
- b. Advanced*
- c. End-stage*

4) To receive comfort-oriented care only, focused only on relieving my suffering such as pain, anxiety, or breathlessness. I would not want to be transported to the hospital or receive any medical intervention that would keep me alive longer.

- a. Advanced*
- b. End-stage*

** Note that although "comfort care only" can be chosen, there are no expectations or restrictions as to what counts as "comfort" measures*

ETHICAL QUESTIONS TO CONSIDER:

- 1) Can a healthy individual's wish to refuse life-prolonging medical treatment if faced with end-stage Alzheimer's be honored through an advance directive?*
- 2) How should we honor the values and wishes expressed in an advance directive if an individual no longer has the capacity to articulate or express such values?*
- 3) Could the ASAP help reconcile disagreements in treatment decisions between surrogate decision makers and other family members (e.g. a decision to place a loved one in a memory care facility)?*
- 4) Must a surrogate decision maker always honor the choices indicated in an advance directive?*

ETHICAL CONSIDERATIONS FOR END-OF-LIFE PLANNING WITH ALZHEIMER'S DISEASE

PART IV: ETHICAL FACTORS IN CONSIDERATIONS OF AID-IN-DYING (AID) IN END-STAGE ALZHEIMER'S DISEASE

Aid-in-Dying Facts

Aid-in-Dying laws are also known as Death with Dignity laws or physician-assisted death laws. According to the Death With Dignity National Center:

"Death with Dignity statutes allow mentally competent adult state residents who have a terminal illness with a confirmed prognosis of having six or fewer months to live to voluntarily request and receive a prescription medication to hasten their inevitable, imminent death."

Aid-in-Dying statutes are effective in:

- California (2016), Colorado (2016), District of Colombia (2016/2017), Hawai'i (2018/2019), New Jersey (2019), Oregon (1994/1997), Vermont (2013), and Washington (2008)
- The Oregon Death with Dignity Act has been in effect for 20 years (approved in 1994, implemented in 1998).
- In 2018, Oregon patients who participated in Death with Dignity indicated that their primary end-of-life concerns were:
 - Loss of autonomy (91.7%)
 - Less able to engage in activities making life enjoyable (90.5%)
 - Loss of dignity (66.7%)

Loss of autonomy, less able to engage in activities making life enjoyable, and loss of dignity have been the **three persistent end-of-life concerns** for participants in Oregon's Death with Dignity Act.

Perhaps, the consistency of patients' fears demonstrates the persistent shortcomings in end-of-life care for the terminally ill. Individuals with Alzheimer's face added barriers to Advance Care Planning due to the progressive loss of cognitive function and decision-making capacity, underscoring the need for a new tool such as the ASAP.

THE ALZHEIMER'S-SPECIFIC ADVANCE PLAN (ASAP) OPENS AN OPPORTUNITY FOR PARTICIPATION IN AID-IN-DYING (AID)

- The ethical implications of an individual with Alzheimer's participating in AiD are profound.
- Individuals with advanced Alzheimer's currently do not meet the legal criteria to participate, and an argument for their participation is an enormous ethical task.
- For this reason, we have not proposed how one may incorporate a request for AiD in the ASAP.
- However, in recognizing Alzheimer's patients as individuals who once possessed medical decision-making capacity and deserve the opportunity to guide their future medical care, AiD is an increasingly frequent aspect of end-of-life advance care planning that warrants consideration, even if only as a hypothetical in most states.

Why ought we consider that end-stage Alzheimer's patients be included in Aid-in-Dying statutes?

One may argue individuals with end-stage Alzheimer's should be allowed to participate in AiD, as Alzheimer's is an incurable, terminal illness, one of the criteria for AiD eligibility. However, Alzheimer's is unique from many other terminal illnesses (e.g. cancer) in that patients experience progressively diminishing mental capacity greatly hindering their ability to guide their own medical care so that by the time they are legally "terminal," they are no longer able to choose. Since we can all imagine what it would be like to lose control of bodily functions, to not recognize loved ones, to forget to eat, we ought to consider allowing Alzheimer's patients to choose, when still capable, how they wish to die in the same way that we allow cancer patients this choice.

This choice to participate in AiD would require that:

- (1) The decision is made and documented **only** when the patient has decision-making capacity; and,
- (2) Participation in AiD occurs **only** in the end-stage of Alzheimer's, and this end-stage diagnosis must be confirmed by two separate physicians, one being a neurologist

ETHICAL CONSIDERATIONS FOR END-OF-LIFE PLANNING WITH ALZHEIMER'S DISEASE

PART IV - CONTINUED

Note that Alzheimer's patients currently cannot choose Aid-in-Dying even in states in which it is legal because they do not meet one or more of the following required criteria for participation:

(1) Life expectancy with an Alzheimer's diagnosis may greatly exceed a six-month time frame

- Alzheimer's is a terminal disease. However, individuals live on average four – eight years after an Alzheimer's diagnosis automatically disqualifying individuals with Alzheimer's from AiD on the basis of the required six-month terminal diagnosis

(2) Individuals with Alzheimer's often lose medical decision-making capacity years before being diagnosed as "end-stage"

- Individuals who reach a six-month life expectancy with Alzheimer's (required to qualify for AiD) lack the decision-making capacity to request and participate in AiD.

(3) Individuals with end-stage Alzheimer's cannot administer Aid-in-Dying drugs without assistance

- Individuals with end-stage Alzheimer's display great difficulty performing every day activities and voluntary motor movements likely impairing their ability to administer the AiD medicine themselves, an AiD disqualification

If AiD were to be an ethical and legally viable option for individuals qualified to create an ASAP, it could be included as a fifth option, permissible only for individuals who meet the criteria for end-stage Alzheimer's in jurisdictions in which it may become legal to do so.

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- Note that the discussion of AiD in end-stage Alzheimer's under the ASAP is not an endorsement per se. Rather, it is an acknowledgment that AiD is a legal choice in an increasing number of states and the District of Colombia for individuals with terminal illness. The laws would need to be amended to allow terminally ill patients with a predicted death beyond six months and those incapable of administering the drug themselves to participate in AiD. Here we wish to provide an ethical framework for such considerations, not an argument in support of or against AiD access for those with Alzheimer's.

Alzheimer's patients' possible choice of Aid-in-Dying raises important concerns about coercion and involuntary participation. However, **carefully crafted** and **robust** regulations governing participation in Aid-in-Dying has the potential to simultaneously function as an acknowledgment of prior patient autonomy and choice, while protecting this vulnerable population from coercion and involuntary participation.

An example of how an AiD option may be formatted and added to the ASAP:

5) To participate in Aid-in-Dying (AiD) in a jurisdiction in which it is legal for me to do so (which currently it is not). If I meet the diagnostic criteria for end-stage Alzheimer's, if I lack self-awareness, and if I have been given approximately six months left to live, I wish to participate in AiD. If I choose this option, both my attending physician and a consulting physician will confirm the diagnosis of end-stage Alzheimer's and the terminal nature of my disease. I understand the implications of this decision and understand that this option will most certainly be carried out in absence of my cognitive awareness. **This option is only appropriate should I meet the qualifications for End-stage Alzheimer's.**

a. End-stage ONLY

ETHICAL QUESTIONS TO CONSIDER:

- 1)** Do we possess enough sense of our future "selves" at full capacity to make a decision in the present for our predictable, but unknown, future selves to participate in AiD?
- 2)** Medically administered nutrition and hydration can be refused via an advance directive. Ought someone living where it is legal to request AiD be able to make that request via an advance directive? Why or why not?

ETHICAL CONSIDERATIONS FOR END-OF-LIFE PLANNING WITH ALZHEIMER'S DISEASE

PART V: ETHICAL CONSIDERATIONS FOR END-OF-LIFE CARE PLANNING IN PATIENTS WITH ALZHEIMER'S DISEASE

Individuals diagnosed with Alzheimer's represent an exceedingly vulnerable population.

The characteristic mental and physical decline of people with Alzheimer's is a significant barrier to honoring an individual's values and goals of care and to following patient wishes for end-of-life care and an opportunity for exploitation.

Considerable effort is being expended on completing advance directives for those diagnosed with Alzheimer's prior to their loss of decision-making capacity. Although these discussions may have occurred a decade or more before the patient enters the terminal stage of the disease, Gaster *et al.* suggest that the "ethical concerns, regarding advance directives in general, have been resolved by considering that enough of a person's identity remains that their previously expressed wishes can still provide useful guidance."

This conclusion rests on the assumption that our medical and moral imaginations allow us to more or less accurately envision the mental and physical decline seen in Alzheimer's, to speculate what it would be like to lose ourselves, and to consider what care and the level of care (e.g., comfort, aggressive) we would wish to receive under such circumstances.

The following brief primarily addresses how we can improve Alzheimer's-specific Advance Care Planning by implementing of the Alzheimer's-Specific Advance Plan (ASAP)

TOP 5 ETHICAL CONSIDERATIONS TO SUPPORT THE ASAP:

1) Individuals with Alzheimer's Disease lose their autonomy as a result of a progressive decline in cognitive function and decision-making ability -- underscoring the need for a way to communicate goals of care in advance.

Unless an individual with Alzheimer's participates in some form of ACP indicating their values and wishes, surrogates, family, friends, caregivers, and health care professionals, will likely be unsure of the patient's values, goals of future care, and desires regarding end-of-life care.

2) End-of-life care planning with Alzheimer's calls for a more organized, specific, and adjustable Advance Care Planning tool, such as the ASAP

(used as a supplement to standard Advance Directives). The ASAP facilitates a more complete conversation and documentation of values and choices than the standard Advance Directive and can be referenced by surrogate decision makers and caregivers when the patient lacks medical decision-making capacity.

3) ASAP implementation contains a protective feature -- it may serve to prevent coercion of a vulnerable patient population and to prevent inadvertent undertreatment or overtreatment that is inconsistent with patient values, when individuals can no longer advocate for themselves.

The ASAP divides Alzheimer's into five stages based on the expected changes in cognition throughout the disease. Based on ethical concerns, an individual's choices for treatment intensity vary depending on the severity of the disease, which can be captured with the ASAP.

4) The ASAP acknowledges the inevitable changes in one's cognitive functioning, behavior, and sense of self and allows an individual to act on his/her documented values even when he/she is incapable of articulating such values.

Standard Advance Directives are most useful in circumstances of sudden loss of decision-making capacity (e.g. stroke, severe trauma, loss of consciousness) but are less helpful in addressing an individual's needs through a progressive, degenerative disease. The ASAP provides a way to consider and create goals of care throughout the progression of Alzheimer's, augmenting the Advance Directive. Implementation of the ASAP for individuals diagnosed with Alzheimer's creates a way for them to think critically about goals of care as the condition of their disease progresses.

5) The ASAP could be configured to include elective participation in Aid-in-Dying for individuals with end-stage Alzheimer's in order to alleviate end-of-life concerns surrounding loss of autonomy, inability to participate in enjoyable activities, and loss of dignity.

Thus far, individuals with dementia have not been able to participate in Death with Dignity statutes, though one may argue that this population has similar end-of-life concerns to other terminal patients.

REFERENCES

PART I: ALZHEIMER'S DISEASE

Part I defines Alzheimer's Disease as a progressive neurodegenerative disorder that can be divided, respectively, into early, moderate, advanced, and end-stage. Each stage of the disease is marked by certain **cognitive** and **behavioral changes** that roughly describe what an individual with Alzheimer's may experience. The purpose is to give readers **background information** about the disease in order to understand how it deteriorates/affects medical decision-making capacity and creates a unique problem for retaining control over one's medical care when capacity is lost.

Sources used:

- (1) "Alzheimer's Disease & Dementia." Alzheimer's Association, Alzheimer's Association, www.alz.org/alzheimers_disease_what_is_alzheimers.asp.
- (2) "What are the 7 Stages of Alzheimer's Disease?" Alzheimers.net, www.alzheimers.net/stages-of-alzheimers-disease/.
- (3) Park, Alice. "Alzheimer's Diagnosis: Disease May Start 18 Years Before Symptoms Appear." Time, Time, 24 June 2015, time.com/3934306/alzheimers-early-diagnosis/.
- (4) Reisberg, Barry. "Clinical Stages of Alzheimer's." Fisher Center for Alzheimer's Research Foundation, Encyclopedia of Visual Medicine Series, 29 Oct. 2015, www.alzinfo.org/understand-alzheimers/clinical-stages-of-alzheimers/.
- (5) Leo, Raphael J. "Competency and Capacity to Make Treatment Decisions: A Primer for Primary Care Physicians." Advances in Pediatrics., U.S. National Library of Medicine, Oct. 1999, www.ncbi.nlm.nih.gov/pmc/articles/PMC181079/.

PART II: ADVANCE CARE PLANNING WITH ALZHEIMER'S

Part II defines Advance Care Planning (ACP), defines Advance Directives, outlines how such planning can be documented in an Advance Directive, and how Alzheimer's Disease affects these processes. Part II discusses the **strengths and weaknesses of standard ACP** in the context of an individual with progressive Alzheimer's Disease. Part 2 also discusses the **repercussions** of having Alzheimer's in absence of adequate ACP, challenging readers to question whether our current system of ACP is unethical, in the way that it puts those with diminishing mental capacity in a vulnerable, powerless position to dictate their future care.

Sources used:

- (1) "Alzheimer's Disease & Dementia." Alzheimer's Association, Alzheimer's Association, www.alz.org/alzheimers_disease_what_is_alzheimers.asp.
- (2) "What are the 7 Stages of Alzheimer's Disease?" Alzheimers.net, www.alzheimers.net/stages-of-alzheimers-disease/.
- (6) Gaster B, Larson EB, Curtis JR. Viewpoint: Advance directives for dementia: Meeting a unique challenge. JAMA 2017; 318(22):2175-2176.
- (7) Kreimer, Susan. "For Your Patients-Dementia: A Proposal to Customize Advance Directives for Dementia Patients." Neurology Today, vol. 18, no. 6, 1 Mar. 2018, pp. 10-11., doi:10.1097/01.nt.0000532090.93630.84.
- (8) Benson WF and Aldrich N. Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself, Critical Issue Brief, Centers for Disease Control and Prevention. 2012. www.cdc.gov/aging.
- (9) "Advance Care Planning: Healthcare Directives." National Institute on Aging, U.S. Department of Health and Human Services, www.nia.nih.gov/health/advance-care-planning-healthcare-directives#what
- (10) "POLST and Advance Directives." National POLST Paradigm, Tides Center, polst.org/advance-care-planning/POLST-and-advance-directives/.
- (11) Yadav, Kuldeep N., et al. "Approximately One In Three US Adults Completes Any Type Of Advance Directive For End-Of-Life Care." Health Affairs, vol. 36, no.7, 2017, pp. 1244-1251., doi:10.1377/hlthaff.2017.0175.

PART III: THE ALZHEIMER'S-SPECIFIC ADVANCE PLAN (ASAP)

Part III is about the **Alzheimer's-Specific Advance Plan (ASAP)**, adapted from the Dementia-Specific Directive proposed by Gaster *et al.* This section defines a dementia-specific directive, outlines it's benefits, and outlines the future directions for these directives. We distinguish the ASAP from the dementia-specific directive, define the audience it applies to, and discuss how to implement the ASAP. The ASAP is specific to Alzheimer's in particular, rather than the broader condition of dementia. We believe that the added degree of specificity warrants additional discussion of specific treatment options.

Sources used:

- (6) Gaster B, Larson EB, Curtis JR. Viewpoint: Advance directives for dementia: Meeting a unique challenge. JAMA 2017; 318(22):2175-2176.
- (7) Kreimer, Susan. "For Your Patients-Dementia: A Proposal to Customize Advance Directives for Dementia Patients." Neurology Today, vol. 18, no. 6, 1 Mar. 2018, pp. 10-11., doi:10.1097/01.nt.0000532090.93630.84.
- (12) Gaster, Barak. "HealthCareDirectives for Dementia." AdvancDirective for Dementia, dementia-directive.org/
- (13) "Patient Navigators Help Cancer Patients Manage Care." Patient Navigators Help Cancer Patients Manage Care, American Cancer Society, 24 Feb. 2017, www.cancer.org/latest-news/navigators-help-cancer-patients-manage-their-care.html

PART IV: ETHICAL FACTORS IN CONSIDERATIONS OF AID-IN-DYING (AID) IN END-STAGE ALZHEIMER'S DISEASE

Part IV introduces Aid-In-Dying (AiD) as a statute that is available and legal in some states, for individuals with terminal diagnoses who wish to end their lives if they should be terminally ill for more than 6 months. This section explains the rationale behind statutes, primary reasons for participation in AiD, and how the **ASAP opens an opportunity for participation in AiD**. This section takes the **grave ethical implications** of such a suggestion very seriously and seeks to recognize this as a due discussion for individuals with capacity who deserve the opportunity to guide their own medical care, even in the face of progressive Alzheimer's Disease. We outline how this **hypothetical option** could be adopted into the ASAP if AiD were a legally viable option for inclusion.

Sources used:

- (14) "Death with Dignity Acts - States That Allow Assisted Death." Death With Dignity, Death With Dignity. www.deathwithdignity.org/learn/death-with-dignity-acts/.
- (15) "Death with Dignity Act Annual Reports." Oregon Health Authority ; Oregon Revised Statute : Death with Dignity Act : State of Oregon, <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ar-index.aspx>

PART V: ETHICAL CONSIDERATIONS FOR END-OF-LIFE CARE PLANNING IN PATIENTS WITH ALZHEIMER'S DISEASE

Part V sums up the ethical issues for end-of-life care planning for patients with Alzheimer's Disease. This section examines the reasons that ACP for these individuals is currently insufficient, and how we may go about addressing this issue, to ensure that all individuals, regardless of the impending deterioration of their health, may be granted the autonomy and respect to choose the circumstances in which they live and die. **We outline the top 5 ethical reasons in support of the ASAP.**

Sources used:

- (6) Gaster B, Larson EB, Curtis JR. Viewpoint: Advance directives for dementia: Meeting a unique challenge. JAMA 2017; 318(22):2175-2176.