Do you suffer from the “**Dementia Fear**”?

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“What is the Dementia Fear?”

An intense fear that drives people to seriously consider, or even act, to hasten their dying while they still can—before they lose either mental or physical capacity. Such acts require sacrificing up to years of reasonably good living—just to be certain they will not “get stuck” in the advanced stage of dementia. Sadly, the author and psychiatrist lost two patients due to the Dementia Fear.

What are its possible dire consequences?

Lack of confidence that others will honor one’s end-of-life wishes can lead some to act on the “Dementia Fear” that this common lament explains:

“If I do not kill myself *now,* when I **can**, then I won’t be able to die *later*, when I would want.”

"Impossible"

THE STATE OF KNOWLEDGE ON ADVANCE REQUESTS FOR MEDICAL ASSISTANCE IN DYING

The Expert Panel Working Group on
Advance Requests for MAID

SOCIETY

The impossible case of assisted death for people with dementia

Is it too much to ask people to follow through on previously expressed wishes for assisted death? An expert report suggests it may well be.

by Shannon Proudfoot May 21, 2019

www.macleans.ca/society/the-impossible-case-of-assisted-death-for-people-with-dementia/

The word "impossible" was used 11 times in a 244-page document by the Council of Canadian Academies, 2018. *The State of Knowledge on Advance Requests for Medical Assistance in Dying*. Ottawa (ON): The Expert Panel Working Group on Advance Requests for MAID, Council of Canadian Academies.

“Pretty slim” and **“Not a Legal Solution”**

“Once the ‘original’ Cantor has been displaced by a pleasantly demented Cantor who is enjoying his chocolate ice cream, the likelihood that the advance directive will be followed is pretty **slim**.”

Avoiding Dementia, Causing Moral Distress

By Dena S. Davis

In “Avoiding Deep Dementia,” an essay in the current issue of the *Hastings Center Report*, legal scholar Norman Cantor explains why he has an advance directive that calls for voluntary stopping of eating and drinking as a means of ending his life if he develops dementia and reaches a particular state of decline.

“Advance Directives are not a legal solution for those who would rather die than suffer years of dementia”

Advance Directives and Alzheimer's Disease

Deena S. Davis

First Published October 18, 2018 | Research Article

https://doi.org/10.1177/1073110518804235

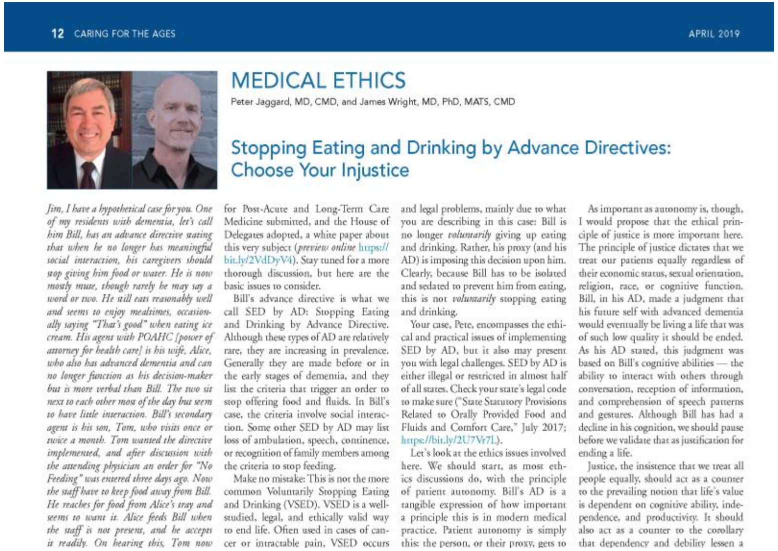
Abstract

Americans who are afraid of living for many years with Alzheimer's might seek a way to end their lives early, when their dementia has just entered the moderate phase. There is no legal process for doing so. In this paper I argue that advance directives, in particular, are not a legal solution for those who prefer to die rather than suffer years of dementia. The problem is that an advance directive only works to hasten death when there is a life-threatening illness for which one can refuse treatment; more often than not, Alzheimer's kills the self long before it kills the body.

Davis, D. S. (2018). Advance Directives and Alzheimer’s Disease. The Journal of Law, Medicine & Ethics, 46(3), 744–748. And: Davis DS. 2018. Avoiding Dementia, Causing Moral Distress. www.thehastingscenter.org/avoiding-dementia-causing-moral-distress/

“providers should refuse…to honor advance directives”

“The Society’s providers should refuse to implement Stopping Eating and Drinking by Advance Directives.”



12 CARING FOR THE AGES APRIL 2019

MEDICAL ETHICS

Peter Jaggard, MD, CMD, and James Wright, MD, PhD, MATS, CMD

Stopping Eating and Drinking by Advance Directives: Choose Your Injustice

Jim, I have a hypothetical case for you. One of my residents with dementia, let’s call him Bill, has an advance directive stating that when he no longer has meaningful social interaction, his caregivers should stop giving him food or water. He is now mostly mute, though rarely he may say a word or two. He still eats reasonably well and seems to enjoy mealtimes, occasionally saying "That’s good" when eating ice cream. His agent with POAHC [power of attorney for health care] is his wife, Alice, who also has advanced dementia and can no longer function as his decision-maker but is more verbal than Bill. The two sit next to each other most of the day but seem to have little interaction. Bill’s secondary agent is his son, Tom, who visits once or twice a month. Tom wanted the directive implemented, and after discussion with the attending physician an order for "No Feeding" was entered three days ago. Now the staff have to keep food away from Bill. He reaches for food from Alice’s tray and seems to want it. Alice feeds Bill when the staff is not present, and he accepts it readily. On hearing this, Tom now

for Post-Acute and Long-Term Care Medicine submitted, and the House of Delegates adopted, a white paper about this very subject (*preview online* https://bit.ly/2VdDyV4). Stay tuned for a more thorough discussion, but here are the basic issues to consider.

Bill’s advance directive is what we call SED by AD: Stopping Eating and Drinking by Advance Directive. Although these types of AD are relatively rare, they are increasing in prevalence. Generally they are made before or in the early stages of dementia, and they list the criteria that trigger an order to stop offering food and fluids. In Bill’s case, the criteria involve social interaction. Some other SED by AD may list loss of ambulation, speech, continence, or recognition of family members among the criteria to stop feeding.

Make no mistake: This is not the more common Voluntarily Stopping Eating and Drinking (VSED). VSED is a well-studied, legal, and ethically valid way to end life. Often used in cases of cancer or intractable pain, VSED occurs

and legal problems, mainly due to what you are describing in this case: Bill is no longer *voluntarily* giving up eating and drinking. Rather, his proxy (and his AD) is imposing this decision upon him. Clearly, because Bill has to be isolated and sedated to prevent him from eating, this is not *voluntarily* stopping eating and drinking.

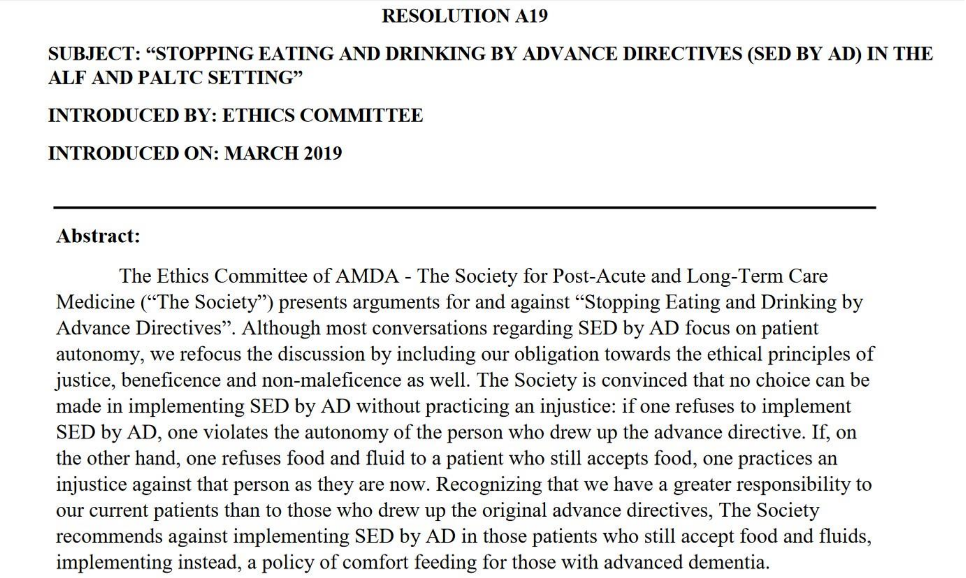
Your case, Pete, encompasses the ethical and practical issues of implementing SED by AD, but it also may present you with legal challenges. SED by AD is either illegal or restricted in almost half of all states. Check your state’s legal code to make sure ("State Statutory Provisions Related to Orally Provided Food and Fluids and Comfort Care," July 2017; https://bit.ly/2U7Vr7L).

Let’s look at the ethics issues involved here. We should start, as most ethics discussions do, with the principle of patient autonomy. Bill’s AD is a tangible expression of how important a principle this is in modern medical practice. Patient autonomy is simply this: the person, or their proxy, gets to

As important as autonomy is, though, I would propose that the ethical principle of justice is more important here. The principle of justice dictates that we treat our patients equally regardless of their economic status, sexual orientation, religion, race, or cognitive function. Bill, in his AD, made a judgment that his future self with advanced dementia would eventually be living a life that was of such low quality it should be ended. As his AD stated, this judgment was based on Bill’s cognitive abilities — the ability to interact with others through conversation, reception of information, and comprehension of speech patterns and gestures. Although Bill has had a decline in his cognition, we should pause before we validate that as justification for ending a life.

Justice, the insistence that we treat all people equally, should act as a counter to the prevailing notion that life’s value is dependent on cognitive ability, independence, and productivity. It should also act as a counter to the corollary that dependency and debility lessen a

“The care of our patients should always be informed by their current experiential interests.”



RESOLUTION A19

SUBJECT: “STOPPING EATING AND DRINKING BY ADVANCE DIRECTIVES (SED BY AD) IN THE ALF AND PALTC SETTING”

INTRODUCED BY: ETHICS COMMITTEE

INTRODUCED ON: MARCH 2019

Abstract:

The Ethics Committee of AMDA - The Society for Post-Acute and Long-Term Care Medicine (“The Society”) presents arguments for and against “Stopping Eating and Drinking by Advance Directives”. Although most conversations regarding SED by AD focus on patient autonomy, we refocus the discussion by including our obligation towards the ethical principles of justice, beneficence and non-maleficence as well. The Society is convinced that no choice can be made in implementing SED by AD without practicing an injustice: if one refuses to implement SED by AD, one violates the autonomy of the person who drew up the advance directive. If, on the other hand, one refuses food and fluid to a patient who still accepts food, one practices an injustice against that person as they are now. Recognizing that we have a greater responsibility to our current patients than to those who drew up the original advance directives, The Society recommends against implementing SED by AD in those patients who still accept food and fluids, implementing instead, a policy of comfort feeding for those with advanced dementia.

The Society for Post-Acute and Long-Term Care Medicine (AMDA) adopted their Ethics Committee’s white paper: bit.ly/2VdDyV4 See also: Jaggard P, Wright J. April 2019. caringfortheages.com/article/S1526-4114(19)30123-4/pdf

“Denied last wish”

The Seattle Times

Local News ▾

Health | Local News | Northwest

Despite advance directive, Oregon dementia patient denied last wish, says spouse

Originally published August 25, 2017 at 2:03 pm | *Updated August 25, 2017 at 11:46 pm*

1 of 4 | Bill Harris walks with his wife, Nora, at the Fern Gardens memory care center in Medford, Oregon. Nora Harris, 64, has late-stage... (Jim Craven/Kaiser Health News) **More**

Nora Harris, 64, a former librarian, signed an advance directive after her diagnosis to prevent her life from being prolonged when her disease got worse. Now, her husband said, she’s being kept alive with assisted eating and drinking against her stated wishes.

By JoNel Aleccia

Kaiser Health News

seattletimes.com/seattle-news/despite-advance-directive-oregon-dementia-patient-denied-last-wish-says-spouse/

Physicians saying "No" can lead to dire consequences.

Sandy Bem, then a Cornell psychology professor, "felt terror at the prospect of becoming a hollowed-out person with no memory, mind or sense of identity, as well as fury that she was powerless to do anything but endure it."

[So] "she vowed that she would figure out a way to take her own life before the disease took it from her."

The Last Day of Her Life

When Sandy Bem found out she had Alzheimer's, she resolved that before the disease stole her mind, she would kill herself. The question was, when?

Photograph from Emily Bem. Photo illustration by The New York Times.

By Robin Marantz Henig

Sandy Bem, a Cornell psychology professor one month shy of her 65th birthday, was alone in her bedroom one night in May 2009, watching an HBO documentary called "The Alzheimer's Project." For two years, she had been experiencing what she called "cognitive oddities": forgetting

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Henig, R. M. (2015). The last day of her life. New York Times Magazine. www.nytimes.com/2015/05/17/magazine/the-last-day-of-her-life.html

DIRE CONSEQUENCES: “A family's anguish as nursing home continues feeding vegetative patient.”

Margot Bentley, a former nurse who was in a vegetative state for years, languished in a Fraser Health-funded nursing home in Abbotsford for a decade. Handout photo [PNG Merlin Archive]

vancouversun.com/news/staff-blogs/medicine-matters-a-familys-anguish-as-nursing-home-continues-feeding-vegetative-patient

“Unresolved questions of great significance to our aging society.” {But must we wait until 2021?}

DEMENTIA AND THE ETHICS OF CHOOSING WHEN TO DIE

Principal Investigators: Nancy Berlinger and Mildred Z. Solomon

Funder: Robert W. Wilson Charitable Trust

In America’s aging society, it is time to explore foundational questions associated with dementia and the concerns of persons facing this terminal condition. This two-year project – one of several planned

The announcement describes the goal and means of a recent research grant and states a “special report” will be “published in 2021.”

Dementia and the Ethics of Choosing When to Die Hastings Center News. June 6, 2019.
www.thehastingscenter.org/news/dementia-and-the-ethics-of-choosing-when-to-die/

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