

Do you suffer from the “**Dementia Fear**”?
If so, what can you do?

Learn how you can overcome common challenges,
potential sabotage,
avoid conflict, and
control the last chapter of your life.

➡ Complete **Strategic Advance Care Planning**

➡ **Plan Now, Die Later[®]—to Live Longer**

Challenges to a timely dying in Advanced Dementia

Authors, societies and committees can influence your future treating physician to say “No”—to refuse to honor your previously expressed end-of-life wishes.

The next page lists some words and phrases that deny YOUR RIGHT to have others honor the advance treatment decisions you want, regarding **when** you want others to allow you to die:



impossible

a fight for the right to die

incredibly difficult

pretty slim

should not be possible

providers should refuse...to honor
advance directives

Doctors who can't talk to patients don't
know what they want

A terrible, great power no doctor should
want and no wise society should grant

Denied last wish

{not mentioning the option to stop
hand-feeding and hand-hydrating}

unresolved questions of great
significance to our aging society

Dementia is old people's greatest fear.

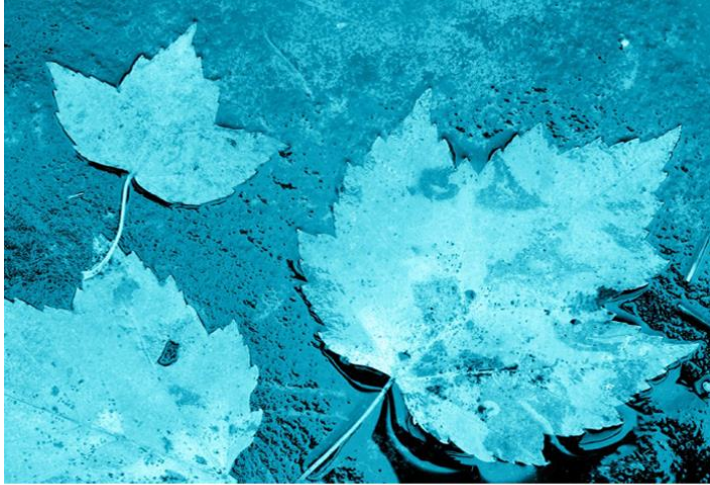
What is the “Dementia Fear”?

And, what are its possible dire
consequences?

Physicians saying “No” can lead to dire
consequences.

Admittedly, the brevity of these out-of-context quotes risks misinterpretation.
See more detailed context and citations to full texts below.

“Impossible”



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

The Expert Panel Working Group on
Advance Requests for MAID

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.

MACLEAN'S

Sign In

Subscribe ▾



AUTHORS ▾



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/



SOCIETY

For people with dementia, a fight for the right to die

The Alzheimer Society of Canada is reconsidering its position on advanced requests for assisted death, amidst a difficult debate about the rights of those with dementia

by [Shannon Proudfoot](#) May 3, 2019

“The truth that underpins the confounding issue of advance requests (advance directives):

“How and when you wish to die is, really, about how you want to live.”

—Shannon Proudfoot

“incredibly difficult”



U.S. World Opinion Politics Entertainment Business Lifestyle TV Fox Nation Listen More :



Login

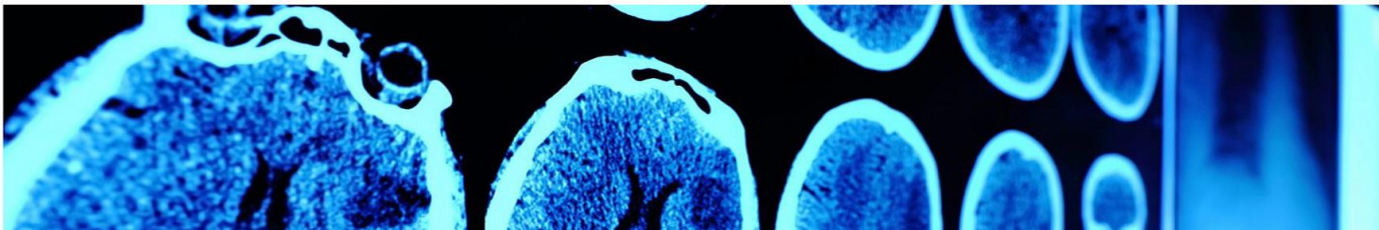
Watch TV

Hot Topics Virginia Beach shooting | Mueller probe fallout | Trump's Mexico tariffs

OPINION · Published December 2

Assisted suicide for Alzheimer's patients raises incredibly difficult issues

OPINION By Josh Bloom, Henry I. Miller | Fox News



Bloom J, Miller H I. Dec 2, 2018. Assisted Suicide for Alzheimer's Patients Raises Incredibly Difficult Issues, Fox News.
www.foxnews.com/opinion/assisted-suicide-for-alzheimers-patients-raises-incredibly-difficult-issues

“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.”

The Hastings Center | Who We Are | Our Issues | Publications & Resources | Support Our Work



BIOETHICS FORUM ESSAY

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. Cantor’s essay and three accompanying commentaries bring up many important points. Let me address one of them, in [Rebecca Dresser’s response](#).

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/

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

SAGE journals

Browse

Resources

Search: keywords, title, autr

Advanced

The Journal of Law, Medicine & Ethics



Advance Directives and Alzheimer’s Disease

[Deena S. Davis](#)

First Published October 18, 2018 | Research Article



<https://doi.org/10.1177/1073110518804235>

[Article information](#)



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.

“should not be possible”

“Because we cannot predict future suffering, providing advance consent for MAID (Medical Assistance In Dying) **should not be possible** for people with dementia...[who] need to be safeguarded as they will be extremely vulnerable at the end of their life.” And,
“MAID should only be possible when a person is deemed competent at the time of MAID.”

| Last updated: December 12, 2018

Alzheimer *Society*

C A N A D A

MEDICAL ASSISTANCE IN DYING FOR PEOPLE WITH DEMENTIA

Position statement

This previously published position statement of the Alzheimer's Society of Canada is currently under review.

“providers should refuse...to honor advance directives”

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

“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

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 non-moving now, though rarely he may sit up or move. He will eat reasonably well and seems to enjoy medications, 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 ([previous online link: https://bit.ly/2VdDyV4](https://www.bit.ly/2VdDyV4)). Say 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 Statutes Provisions Related to Advance Provided Food and Fluids and Comfort Care," July 2017; <https://bit.ly/2U7V7L1>).

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 his modern medical practice. Patient autonomy is simply this: the person, or their proxy, gets so

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 covetous that dependency and debility lessen a

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](https://www.caringfortheages.com/article/S1526-4114(19)30123-4/pdf)

“Doctors who can’t talk to patients don’t know what they want”

Dutch medical ethicist Berna van Baarsen was quoted by Andrew Bomford as saying: “Before helping someone to die, doctors must always check that this is still the patient's wish. And with late-stage dementia patients, this is not always possible. ‘If you can't talk to a patient, you don't know what the patient wants.’”

Wanting to die at 'five to midnight' - before dementia takes over

By Andrew Bomford
BBC News

© 30 January 2019

f     Share



It's not unusual for Dutch patients with dementia to request euthanasia, but in the later stages of the disease they may be incapable of reconfirming their consent - one doctor is currently facing prosecution in such a case. But fear

in BBC News 30 January 2019. Everyone wants to wait until the last possible moment before they leave the party - until five to midnight - but many feel that it's too risky to leave it that long. www.bbc.com/news/stories-47047579.

See also: 'Euthanasia in incapacitated dementia patients cannot be defended' Society Edwin Kreulen- 6:00, January 13, 2018. www.trouw.nl/samenleving/-euthanasie-bij-wilsonbekwame-dementiepatienten-is-niet-te-verdedigen-~a70bdd45/

“A terrible, great power no doctor should want and no wise society should grant”

Hastings Center Report / Volume 48, Issue 4

Other Voice |  Free Access

An Open Letter to Norman Cantor Regarding Dementia and Physician-Assisted Suicide

Daniel P. Sulmasy

First published: 16 August 2018
<https://doi.org/10.1002/hast.868>



“If a physician acts with the intention of making someone dead, or help someone to make herself dead, because the physician cannot otherwise cure or relieve the suffering that she has deemed unacceptable, then the physician has, in effect, refused to accept the limits of medicine. Medicine becomes the ultimate solution to the problem of human suffering. That is a terrible power—a power so great that it cannot help but be corrupting. It is a power no doctor should want and no wise society should grant to its healers.”

Sulmasy D. Aug. 2018. An Open Letter to Norman Cantor Regarding Dementia and Physician-Assisted Suicide. onlinelibrary.wiley.com/doi/full/10.1002/hast.868.

Daniel Sulmasy, PhD, MD, and Franciscan Friar, is the Acting Director of the Kennedy Institute of Ethics, a faculty member of the Pellegrino Center for Clinical Bioethics, and the inaugural Andre Hellegers Professor of Biomedical Ethics at Georgetown University (Departments of Philosophy and Medicine).

“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/

{not mentioning the option to stop hand-feeding and hand-hydrating}

alzheimer's  association®

Feeding Issues in Advanced Dementia

“The Association...endorses the use of advance directives” and,
“encourages surrogates to discuss the risks and benefits of all feeding alternatives with the medical care team to arrive at a choice that ensures the highest quality of care and is consistent with the person’s values.”

Yet the Alzheimer’s Association 777-word 2015 position statement considered only two choices: tube-feeding and careful hand-feeding.

Alzheimer’s Association. 2015. Feeding Issues in Advanced Dementia www.alz.org/media/Documents/feeding-issues-statement.pdf. This option has been discussed a long time. See for example: Lynn, J. *No Extraordinary Means. The Choice to Forgo Life-Sustaining Food and Fluid*. 1986, Indiana University Press.

Dementia is old people's greatest fear.

HUFFPOST

Deborah Gale, Contributor
Ageing aficionado

Why Dementia Is The Mother Of All Boomer Fears

03/11/2016 08:07 am ET | Updated Mar 12, 2017

Dementia's got us all hepped up, with worry. The "forgetting" is epidemic and it's the fear of losing ourselves. And it has penetrated the consciousness of humanity since the time of Aristotle.

www.huffpost.com/entry/dementia_b_9375396

www.dailymail.co.uk/health/article-2715049/We-fear-dementia-cancer-Two-thirds-50s-fear-brain-condition.html

www.dailymail.co.uk/health/article-2947718/We-scared-getting-dementia-old-age-disease.html

Daily Mail
.com



health

Home | U.K. | News | Sports | U.S. Showbiz | Health | Science | Money | Video | Travel | Columnists | DailyMailTV

Latest Headlines | Health | Health Directory | Games

Login

We're more scared of getting dementia in old age than any other disease such as stroke, cancer and heart disease

- More people fear dementia than stroke or heart disease, a survey found
- Some people say the results show people are talking about dementia
- People worry they won't be able to afford to care for their elderly relative
- Care for dementia sufferers can cost from about £750 to £1,400 per week

By MADLEN DAVIES FOR MAILONLINE

PUBLISHED: 19:05 EDT, 10 February 2015 | UPDATED: 03:05 EDT, 11 February 2015

Dementia is our most feared disease - overtaking cancer, strokes and heart disease, a survey has found.

The condition, which gradually destroys the sufferer's memory and personality, is feared by a third of people aged over 55.

This compares to only a tenth who say they are afraid of suffering a stroke, which is Britain's number four killer.

And only four per cent who say they are afraid of heart disease - the country's number one cause of death.

“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.”

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

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

Physicians saying “No” can lead to dire consequences.

MARCH 20, 2019

Her Time

Debra Koosed was diagnosed with dementia at 65. That's when she decided she no longer wanted to live.

By Katie Engelbart

Illustrations by Nick Runge



Her Time

The California Sunday Mag.
Story.californiasunday.com


Engelbart, K. 2019. Her Time. California Sunday. story.californiasunday.com/assisted-suicide
(Illustrations by Nick Runge)

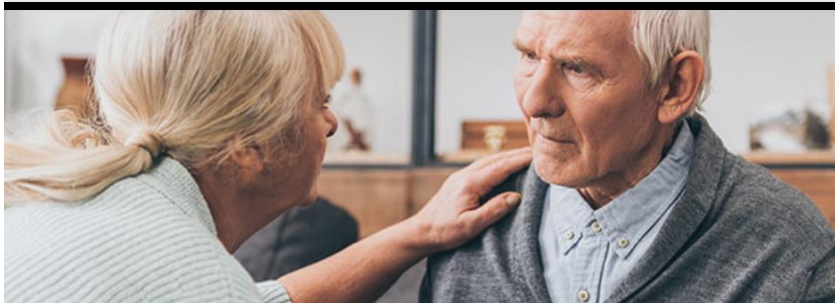
DIRE CONSEQUENCES: “A family's anguish as nursing home continues feeding vegetative patient.”



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]

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

 The Hastings Center | Who We Are | Our Issues | Publications & Resources | Support Our Work



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/

You can make your living will requests clear, consistent, convincing, and compelling by completing the (*patent pending*) program, **Strategic Advance Care Planning.**

If you can have confidence in this program, you can feel peace now,

And you can then live by this slogan:

Plan Now, Die Later[®]—to Live Longer.

