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.

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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.”
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.”

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

The Society for Post-Acute and Long-Term Care Medicine (AMDA) adopted their Ethics Committee’s white paper:


RESOLUTION A19

SUBJECT: “STOPPING EATING AND DRINKING BY ADVANCE DIRECTIVES (SED BY AD) IN THE ALF AND PALTIC 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.
“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

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.”

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