The Top Five Reasons Why Living Wills Won’t Work for Alzheimer’s Dementia

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Presentation Outline

1. Confidence in end-of-life planning is important.
2. Living Wills must answer two questions.
3. The Top Five Reasons Why Living Wills Won’t Work for Alzheimer’s and related dementias.
4. What will you conclude, and then decide? Will you have enough confidence in end-of-life planning to decide on living?
Conclusions (See if you agree, later.)

A. Not having confidence in your living will could lead you to consider and then act to end your life prematurely since...

B. If your living will won’t work, your dying could be prolonged with severe suffering...

C. Yet with the right effort, you can attain your goal—a timely dying—so this slogan is apt:

⇒ Plan Now, Die Later®—to Live Longer
Are these your end-of-life goals?

- To have a private, peaceful, and timely dying, and
- To avoid a prolonged dying with severe suffering,
  —where “timely” means neither prolonged nor premature—and is based on your personal values.
Confidence in end-of-life planning is important to avoid two types of sad stories:

“Let’s not treat mom’s pneumonia. Then we can be sure she won’t suffer for years in advanced dementia, like her mother did.”
—An existential conundrum of concerned loved ones, which they commonly act on.

“If I don’t kill myself now, while I still can, then I won’t be able to die later, when I would want.”
—Suicide is likely under-reported. This lament causes many patients daily anxiety: the “Dementia Fear” →
The “Dementia Fear”

If you have risk factors for dementia, or a diagnosis of mild cognitive impairment or early dementia... would you have this fear?

“If I wait too long to kill myself, my dementia will progress and cause me to lose the ability to control when and how I die. I fear becoming ‘stuck’ in advanced dementia for several years.”

—This “Dementia Fear” can lead to premature dying that can be tragic because it requires sacrificing months to years of reasonably good living, and can be unnecessary since there is an alternative: You can...

➔ Complete an end-of-life plan in which you feel confident will be effective. Then you can live until your suffering becomes severe.
Read, if you’re concerned about a loved one with dementia:

Suppose you are a decision-maker for a loved one now living with Mid-Stage Dementia who cannot make medical decisions. Yet s/he can still enjoy the simple pleasures of life. Then, one day, s/he gets pneumonia.

You could use this “opportunity” to make sure s/he will never reach Advanced Dementia. You could refuse all treatment—to let him/her die.

But life is worth living until suffering becomes severe.

➔ If you feel confident end-of-life planning can help your loved one attain his/her end-of-life goal based on severe enough suffering, then...

You will request a trial of full treatment that includes antibiotics for a reasonable time. You will give your loved one this better opportunity: the possibility to recover and to continue living.
Which Two Questions Must Living Wills Answer?

If you no longer can speak for yourself, Your Living Will must answer:

“WHAT (treatment) do you want, or not want?”

and, WHEN?”
The Top Five Reasons Why Living Wills Won’t Work for Dementia

1. The “WHAT” is not effective.
2. The “WHAT” is not acceptable.
3. The “WHEN” relies on criteria that are vague, irrelevant, and/or dangerous.
4. The “WHEN” uses criteria physicians will not likely consider compelling.
5. Advance Care Planning did not include the extra effort to be convincing, to overcome physicians’ resistance, or to prevent sabotage by others.
1 a. The “WHAT” is not effective.

A “WHAT” that stops all life-prolonging treatment is often necessary, but not sufficient.

The reason: Sustaining the lives of many advanced dementia patients does not depend on high-tech medical treatment. They have “No Plug to Pull.”

Living wills that request, “Stop all medical treatment,” may not allow advanced dementia patients to die.

➔ Living wills must make this specific request: “Stop all oral intake of nutrition and hydration.”
1 b. The “WHAT” is **not** effective: example.


This brochure advises against tube-feeding. It recommends: “other ways to feed a person with late-stage Alzheimer’s, such as by careful hand feeding. For someone who can no longer swallow, an approach focusing on comfort in dying may be most appropriate.”

Also: “Refusal or withdrawal of treatment, including tube feeding, antibiotics or CPR, is **not assisted suicide (euthanasia)**. Limiting treatments lets the disease take its **natural course** and supports the person’s **comfort** and **dignity**.”

- But their next recommendation is vague: “Use advance directive forms that are **recognized** in [your] state.”

- This brochure does **not suggest a living will** that lets you refuse oral feeding by **mouth**; eg, **spoon-feeding**.
2. The “WHAT” is not acceptable.

**Withholding** oral food and fluid from a patient, even if the patient had **clearly** requested it previously, can lead others to view the compliance by others as **euthanasia**, which is **illegal**.

**Natural Dying**, in contrast, only **withdraws** assistance with hand-feeding & hand-hydrating. It **always offers** patients food & fluid by placing them in front of, and within patients’ reach.

**Natural Dying** allows patients to die of their underlying disease. It strives to be viewed as clinically appropriate, legal, ethical, moral, and consistent with teachings of most major religions.
3 a. The “WHEN” relies on criteria that are vague, irrelevant, and/or dangerous. 


Decision-makers should be guided by this laudable principle:

It is morally optional to discontinue a treatment if its harm and burdens outweigh its benefits.

Yet applying this principle by itself, to patients who are dying slowly, is so vague that it often invites conflict that delays or thwarts attaining a private, peaceful, and timely dying.
3 b. The “WHEN” relies on criteria that are vague, irrelevant, and/or dangerous

Irrelevant: behavior during spoon-feeding (part 1).

If the patient resists spoon-feeding, it might be not because s/he wants to die, but because s/he has severe pain in his/her GI tract. Example: a toothache or severe constipation, which the patient is not able to tell others is causing pain.

Physicians who stop spoon-feeding without looking for, and then treating the cause of a patient’s pain, may let their patient die prematurely.
⇒ Physicians need to be cautious and not presume it is easy to judge their patients’ “Best Interest.”
3 c. The “WHEN” relies on criteria that are vague, irrelevant, and/or dangerous

**Irrelevant: behavior during spoon-feeding** (part 2).

If the patient *seems* to cooperate by opening his/her mouth and swallowing what others put in, s/he still may want to die. Cooperation during feeding could be due to reflex, habit, wanting the last vestiges of social attention from others, or reflect the patient’s inability to show any kind of resistance because dementia caused severe loss of functioning.

If these or similar reasons apply, then the patient’s dying could be *prolonged*—possibly with severe suffering that could increase. ➔ Physicians need to be cautious and not presume it is easy to judge their patients’ “Best Interest.”
3 d. The “WHEN” relies on criteria that are vague, irrelevant, and/or dangerous.

Irrelevant: reaching a clinical stage or condition of disease because patients cannot tell others if they are suffering.

Reaching a clinical condition or stage of a disease does not necessarily imply the patient will then be suffering.

For patients who are **not suffering**, using this criterion could be arbitrary... irrelevant... or worse:

- Patients who use this criterion may **discriminate** against themselves, as an older people who has cognitive impairment by judging their demented future selves **not** deserving to live.
3 e. The “WHEN” relies on criteria that are vague, irrelevant, and/or dangerous

Dangerous: some commonly used terms.

The terms, unbearably low “quality of life,” and intolerably severe “indignity,” are often used as criteria. ➔ But they are not just vague; they could be dangerous.

Using these terms could begin a slippery slope that may lead one group of people to presume they can judge whether or not the lives of others are (still) worth living. History has sadly recorded enormous harms that began this way.
4 a. The “WHEN” relies on criteria that physicians are not likely to consider compelling.

The most compelling reason to justify allowing a patient to die is irreversible severe suffering. Admittedly, applying this standard is challenging:

(A) Advanced Dementia patients cannot inform others if their suffering is severe; and,

(B) Physicians’ interpretation of observed behavior could be wrong.

One solution broadens the concept of suffering and asks patients to pre-judge the suffering of conditions.
4 b. The “WHEN” relies on criteria that physicians are not likely to consider compelling

In addition to physical pain, suffering can include:

- Emotional or psychic turmoil;
- Existential suffering;
- Suffering due to the disruption of one’s life narrative; and,
- Not being able to spare loved ones the burdens of one’s disease, which in turn leads to various types of suffering. (Explained in detail, elsewhere.)
4 c. The “WHEN” relies on criteria that physicians are not likely to consider compelling.

Instead of asking physicians this clinical question: “Please evaluate this advanced dementia patient to determine if his/her suffering is now severe…”,

A living will can ask patients this question: “Do you judge this condition would cause you severe enough suffering to want others to allow you to die of your underlying disease?”

Then physicians could be asked this easier question: ➔ “Has the patient reached this clinical condition?”
5 a. Advance Care Planning did not include the extra effort... to be convincing, to overcome the resistance of physicians, or to prevent sabotage by third parties.

Checking a few boxes on a form cannot prove...
Your decision-making was diligent and deliberative; or You had sufficient mental capacity (competence) as you expressed your requests for end-of-life treatment. Checking boxes cannot provide you the opportunity to convincingly explain your treatment preferences.

➤ So record your responses to an interview on video.
5 b. Advance Care Planning did **not** include the extra effort... to be convincing, to overcome the resistance of physicians, or to prevent sabotage by third parties.

Add to your advance directive, specifically designed **strategies** designed to overcome physicians’ resistance, and to prevent sabotage by third parties. These **strategies** took years to develop with input from clinicians, bioethicists, attorneys, and members of the clergy. (Beyond the scope of this presentation.)

In life, solutions to complicated problems are rarely simple. (More details are available )
Physicians can disregard living wills that request stopping oral feeding. Instead, physicians can continue spoon-feeding until they interpret patients’ behavior as refusal or distress. In March 2019, a society of leading physicians who care for patients in assisted living and skilled nursing facilities voted to adopt a resolution to make this clinical decision their policy.

Strategies to overcome physicians’ disregarding patients’ living wills include: interpreting refusal or distress may be wrong; it is ethically wrong to violate patients’ autonomy; and, it is ethically right to let patients choose who decides as based on their personal values—as they complete their living will.
To Gain Confidence in End-of-Life Planning —for Yourself, or for Your Loved One

The web site www.CaringAdvocates.org describes “Strategic Advance Care Planning” for yourself, and “Now Care Planning” for your loved one. Click to read or download the PDF, “Six Steps...” for more detail.

Especially recommended: Step Five of “Six Steps to Strategic Advance Care Planning.” This step introduces strategies that strive to overcome more than 14 challenges and obstacles.

➔ By itself, even the best living will may not be effective.

Also important: Case law further reveals that by themselves, proxies/agents may not be effective unless backed by evidence in a clear and specific living will, which others can view as acceptable.
Conclusions (Do you agree now?)

A. Not having confidence in your living will could lead you to consider and then act to end your life *prematurely* since...

B. If your living will won’t work, your dying could be *prolonged* with severe suffering...

C. Yet with the right effort, you can attain your goal—a *timely* dying—so this slogan is apt:

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Do you have enough confidence in end-of-life planning to decide on living?

End-of-Life Planning is not 1 of the 2, 100% certain things in life. One authority is precisely what our planning effort tries to avoid: A lawsuit leads to a court of legal appeals setting a precedent. The much preferred authority: Clinicians make decisions at your bedside, privately, in the “court of clinical action.”

Do you have confidence that with sufficient effort, you can attain your end-of-life goals? What will you conclude and then decide?

⇒ “I’m willing to sacrifice some years of living by pre-emptive suicide,” or: ⇒ “I want to Plan Now, Die Later®—to Live Longer”? 
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