Society of Medical Education & Research

2023, Volume 3, Page No: 126-150
ISSN: 3108-5059

Asian Journal of Ethics in Health and Medicine

Limitations of Advance Directives on Withdrawing Assisted Feeding in Late-Stage Dementia and Their Impact on Timing of Death

Ayuk Patricia[1*]

[1] Department of Theology and Religious Studies and School of Nursing and Health Professions, University of San Francisco, San Francisco, USA.

***E-mail** ayukpatrica@outlook.com

Abstract

Advanced Alzheimer's disease and other late-stage dementias can lead to a prolonged, distressing terminal phase, often lasting years when caregivers continue oral feeding and hydration. Options to prevent extended dying are limited because patients with advanced dementia are ineligible for Medical Aid in Dying. Legal and medical authorities frequently require clear, convincing proof of a patient's wish to die—something many advance directives fail to provide. Substituted judgment by proxies or agents may also diverge from the patient's true desires. While advance directives represent a potential last recourse for achieving a dignified and timely death aligned with a patient's lifelong values, their effectiveness depends on being both enforceable and acceptable. Even a single flaw can justify refusal by opponents to honor requests to discontinue assisted feeding. This article examines 24 common shortcomings in advance directives, organized into four categories. Process flaws concern the manner in which patients articulate their end-of-life preferences. Content flaws involve the choice and description of medical conditions and interventions. Inherent flaws may render directives unacceptable to authorities wary of premature death. The discussion also addresses strategies to ensure physicians issue necessary orders and to prevent third parties from undermining them. Excerpts from dementia-specific directives or supplements—primarily from the US and Europe—illustrate each flaw. None of the directives reviewed contained an effective method for resolving a longstanding ethical conflict: the directive requests "Cease assisted feeding," yet the incapacitated patient seems to indicate a desire to "Continue assisted feeding." Some critics use this apparent conflict to justify strict paternalistic intervention. This article proposes a protocol aimed at preventing such conflicts, potentially reducing the need for authorities to impose additional clinical criteria before honoring patients' directives. By highlighting common flaws, this critique provides guidance for drafting and selecting advance directives that are more likely to be effective and respected in dementia care. It also raises important ethical and clinical questions for those in positions of authority: Does paternalistic refusal to honor a patient's wishes truly uphold self-determination? Does it protect vulnerable patients from harm, or does it instead prolong suffering? Does it align with bioethical principles and the core tenets of patient-centered care?

Keywords: Paternalism, Late-stage dementia, Advanced dementia, Advance directives, End-of-life decision-making, Advance care planning, Ceasing assistance with oral nutrition and hydration, Suffering in dementia, Voluntarily stopping eating and drinking

Background

Access this article online https://smerpub.com/

Received: 16 October 2023; **Accepted:** 18 December 2023

How to cite this article: Patricia A. Limitations of Advance Directives on Withdrawing Assisted Feeding in Late-Stage Dementia and Their Impact on Timing of Death. Asian J Ethics Health Med. 2023;3:126-50. https://doi.org/10.51847/NTDZo2ypPf

Advanced dementia represents a prolonged, burdensome, and distressing terminal illness

Surveys in the UK indicate that over half of people fear a dementia diagnosis, with 62% equating it to the end of life [1]. Many individuals engage in advance care planning to avoid enduring a prolonged dying process during late-stage dementia. This disease, regardless of its subtype, progressively erodes memory, alters personality, diminishes cognitive function, impairs communication, and often leads to embarrassing or

hazardous behaviors. Patients ultimately become completely dependent on others for daily care. Less recognized is that individuals may experience severe, undiagnosed physical pain once they lose the ability to express it.

Dementia also imposes substantial emotional, physical, and financial strain on family members and caregivers, whose burdens often persist long after the patient can no longer recognize or enjoy their presence. Conventional advance directives frequently overlook suffering that is not immediately observable, leading some clinicians to dismiss patients' distress with comments such as, "She is just sitting there." Yet suffering in advanced dementia can stem from sources that are invisible to observers, including disruption of life narrative, the creation of unwanted or negative memories for loved ones, and extreme social isolation resulting from profound cognitive decline. These sources contribute to existential suffering, which cannot be alleviated through medical treatment. Patients may also endure emotional suffering manifested as withdrawal, which often goes untreated because it does not present a clinical management problem.

The scope of the issue is considerable: currently, one-third of individuals over 65 die with dementia [2], and projections suggest that by mid-century as many as one in twelve people over 65 could be living with advanced dementia [3].

This article examines advance instructional health care directives—commonly known as living wills or advance decisions (UK)—and uses the term "directives" throughout, including when referencing instructional supplements. (A companion article addresses challenges with relying on surrogates to enact patients' end-of-life preferences.) The article first explains why directives may serve as a final safeguard against prolonged dying in advanced dementia. It then analyzes 24 common flaws—one by one—that can hinder their effectiveness. Here, "success" is defined as achieving compliance from future treating physicians, so that orders align precisely with the directive's requests. Most examples are drawn from US sources, as many other countries emphasize shared decision-making conversations rather than standardized forms. Nonetheless, the insights gained from flawed directives can inform physician–patient discussions, guiding clinicians to ask the right questions. The article concludes on an encouraging note, presenting two examples of successful directives, while the Appendix provides a detailed analysis of flaws in a widely used directive.

Limited options for alleviating suffering in advanced dementia

Currently, no medications have definitively proven effective in preventing dementia, delaying its onset, or slowing its progression [4, 5]. Medical Aid in Dying—often considered a form of physician-assisted suicide—is generally inaccessible to patients with dementia because they typically fail to meet two essential criteria: decision-making capacity and a prognosis of likely death within six months (applicable in roughly ten US jurisdictions).

While appointing a proxy or agent as a surrogate decision-maker is critical [6–9], physicians, administrators, and courts may ignore their guidance unless clear and convincing evidence exists that the patient intended to forgo all life-sustaining interventions. For instance, a court denied the request of Norah Harris's husband and proxy, consistent with the 1990 US Supreme Court decision in Cruzan v. Director, Missouri Department of Health [10–12], which affirmed that states may require clear and reliable evidence before honoring treatment refusal for another person.

A well-recognized challenge is the frequent lack of alignment between proxies' or agents' decisions and patients' wishes [13]. Although proxies and agents generally act with genuine concern for their loved ones, most lack the training, experience, or persuasive skills necessary to overcome resistance from medical professionals or administrators when advocating for controversial directives. Margaret Bentley's case, in which she was force-fed for five years, exemplifies this difficulty [14, 15].

Moreover, following proxy instructions does not always reflect the patient's desires. A review by Dening *et al.* [16] identified the potential for proxy decisions to diverge from the preferences of persons with dementia as a major barrier to successful advance care planning. Using a nominal group technique with UK participants, Dening further noted that many caregivers believe they are honoring their family member's wishes, but in reality, their choices are often influenced by their own experiences and may not align with what the patient would have wanted if still competent [17].

When advanced dementia cannot be prevented, delayed, or effectively treated, and patients are ineligible for Medical Aid in Dying, achieving a dignified and timely

death depends largely on advance directives. Yet these directives must meet more than one criterion: they need to accurately reflect the patient's wishes, be enforceable in clinical practice, and gain acceptance from medical and legal authorities. In isolation, directives may not suffice. Patients often require additional measures to ensure physicians issue the necessary orders and to safeguard against interference by others once those orders are in place.

Fagerlin and Schneider observed in 2004 that, despite the intuitive appeal of living wills, they frequently fail in practice, noting that the challenge lies not in effort but in the inherent difficulty of creating functional forms [18]. Nonetheless, the past decade has seen the development of numerous dementia-specific directives in the US (2014–2020), which this article examines and critiques.

Complexities of end-of-life directives in advanced dementia

Many individuals in the late stages of dementia can survive for years without intensive life-sustaining treatments. In other words, there is often no immediate intervention to withdraw. For patients wishing to avoid prolonged dying, ceasing assisted feeding—which includes both nutrition and hydration—can provide a peaceful and attainable end-of-life pathway, as dependency on caregivers for these needs is nearly universal in advanced dementia [19, 20].

Requests to stop assisted feeding are highly controversial. Cultural norms often equate food with care and feeding with love, leading some to view withdrawal of nourishment as cruel. However, in patients with terminal dementia, opening the mouth to accept food may be purely reflexive rather than a true expression of desire. Continuing feeding under such conditions can prolong dying and associated suffering, often unnoticed.

Bioethically, the principle of prioritizing patient preferences is central. According to Opinion 2.20 of the American Medical Association's Code of Ethics, physicians are charged both to preserve life and alleviate suffering, and when these obligations conflict, the patient's wishes should guide care [21].

Purpose of this review

This article identifies 24 recurring flaws in advance directives—not to single out individual documents, but to alert readers and guide future drafting and clinical conversations. The critique draws upon the directives themselves, clinical experience, and literature, recognizing that comprehensive outcome data may take years to accumulate. Some ethical considerations, such as directives for individuals seeking maximal longevity, fall outside the scope of this discussion [22].

To reduce ethical tension surrounding orders to cease assisted feeding, this review emphasizes two key standards. First, individuals engaged in advance care planning (planning principals) must clearly define the circumstances in which suffering becomes intolerable and justifies the decision to die, according to their personal values. Second, the underlying disease must remain the ultimate cause of death, even though the timing may be influenced by decisions from physicians or proxies regarding withdrawal of assisted feeding.

The serious consequences of disregarding directives

Failing to honor advance directives can have two major repercussions: (A) prolonged dying accompanied by severe suffering, and (B) premature death driven by patients' fear of dementia. The latter occurs when patients, doubting that their wishes will be respected, attempt to hasten death before losing decision-making capacity, in order to avoid enduring years of misery in advanced dementia. For example, Still Alice [23] was unable to follow her previously written directives by the time she met her criteria for wanting to die. Attorney and bioethicist Dena Davis [24] has suggested that preemptive suicide prior to losing capacity might be the only guaranteed way to avoid prolonged suffering from dementia. However, such actions may cut short years of relatively good life. This article emphasizes the importance of drafting directives that avoid common pitfalls, allowing patients to trust that their wishes will be respected and reducing any inclination to hasten death prematurely.

Key requirements for effective directives

All instructional directives follow a basic "If…Then" structure:

If a specific condition arises, then a particular intervention is desired.

To be successful, directives must answer two critical questions: the When (the "If") and the What (the "Then"). The When must clearly define the circumstances under which life-sustaining treatments should be withdrawn, avoiding ambiguity or conflict. The What must outline interventions that are both

effective and acceptable. For instance, medical dehydration is an effective method, as death usually occurs within two weeks, and studies suggest the process can be peaceful—for example, in hospice patients who remain alert [25]. Acceptability requires that authorities—medical, legal, ethical, cultural, and possibly religious—recognize the patient's request to cease assisted feeding as appropriate and legitimate.

The limitation of purely descriptive definitions of directives

A common mistake is evaluating directives solely based on descriptive definitions. For example:
Descriptive definition: An instructional directive is a form completed by a planning principal to inform healthcare providers of their treatment preferences in the event of future incapacity and specified clinical conditions.
Operational definition: An instructional directive is a form completed by a planning principal in anticipation of future incapacity to provide evidence that proxies or agents can use to convince treating physicians and other healthcare providers to promptly implement orders aligned with the principal's treatment preferences, while preventing interference from third parties.
A directive may appear successful when assessed descriptively, yet fail operationally when it is put into practice. Achieving self-determination through advance directives requires that planning principals' stated wishes translate into actual medical orders that are respected in the future.
For instance, a Nevada statute [26] attempts to address the What question but fails to clarify When. While it legally permits ceasing assisted feeding, its vague language—"You can…state what you want to happen if you get very sick and are not likely to get well"—has raised concerns, as noted by Thaddeus Pope [27]: "When do we stop offering food and fluids? How do we ascertain whether any specified 'trigger' conditions are met?" This highlights the difficulty planning principals face in drafting statements that are persuasive, clear, and convincing. Flawed directives have contributed to controversial cases, such as one in the Netherlands, illustrating the danger of ambiguous or inconsistent descriptions.

Several authors of dementia-specific directives have openly acknowledged that their enforceability remains questionable

Jonathan Patterson, an attorney with Compassion & Choices, observed that even well-written instructions may not necessarily be respected by medical staff [28]. Judith Schwartz, representing End of Life Choices New York, pointed out that the "Advance Directive for Receiving Oral Foods and Fluids in the Event of Dementia" [29] (NY Directive) still lacks judicial validation. Similarly, the team behind Compassion & Choices' "Dementia Values and Priorities Tool" [30] (CGC Tool) cautioned that healthcare professionals and advocates fear accusations of elder abuse if they comply. The creators of the "Supplemental Advance Directive for Dementia Care" [31] (SADD) also admitted that state laws offer little clarity about whether providers are legally obligated to carry out a request for VSED.

Conclusion

This short review highlights the necessity of producing directives that are not only precise and persuasive but also designed to remain binding and resistant to revocation. Directives that can independently guide care are preferable to those relying heavily on proxies, agents, or physicians to interpret and enforce patients' wishes. Such concerns are particularly pressing for individuals with advanced dementia. The following sections examine the most frequent flaws that undermine the effectiveness of directives.

Categories of flaws

In this analysis, a "flaw" refers to any weakness within a directive or its supplement that renders it vulnerable to rejection or misapplication, thereby preventing individuals from achieving their intended end-of-life outcomes.
The discussion is divided into two main parts:
Part One reviews flaws occurring when competent individuals draft their directives:
- Type I flaws (1–6): issues in the drafting process itself, reflecting how individuals articulate their wishes.
- Type II flaws (7–13): issues in directive content, including the medical conditions and interventions chosen and the manner of their description.

Part Two examines flaws that emerge once patients with advanced dementia lose decision-making capacity and directives are put to the test:

- Type III flaws (14–19): inherent weaknesses, such as interventions that fail to achieve their purpose or provisions that authorities deem unacceptable.
- Type IV flaws (20–24): omissions of strategies that could obligate physicians to act on patient requests or prevent external parties from undermining those actions.

PART ONE: Errors that occur while planning principals prepare their directives

Illustration: Margaret Bentley's directive and its shortcomings

As a young nurse, Margaret Bentley witnessed firsthand the slow decline of patients with advanced dementia, and those experiences convinced her that she never wanted to endure the same drawn-out dying. When she later confronted her own risk of dementia, she attempted advance care planning. However, in 1991 British Columbia lacked legal statutes on directives, leaving her to draft one herself. She also appointed her husband and daughter—a nurse—as surrogate decision-makers, both of whom pledged to honor her wish to avoid a prolonged dying.

Despite these safeguards, her husband and daughter were unable to persuade physicians, care administrators, or the courts to respect her instructions. Instead, she endured five years of forced feeding, with considerable suffering, including severe joint contractures and pain during transfers from bed to chair. She eventually succumbed after years of progressive starvation, her physical condition compared to that of a concentration camp survivor [15].

Why did her directive fail? Nursing home officials, acting under the guise of patient protection, revoked a physician's initial order to stop assisted feeding. They escalated matters by initiating an elder abuse inquiry and securing a restraining order to prevent her family from moving her home, where her wishes might have been followed. In subsequent court hearings, an "expert" with little qualification testified—without challenge—that her willingness to open her mouth for food, and preference for sweets, signified a desire to continue eating. This was interpreted as her changing her mind, undermining her original directive.

The directive's critical flaws included:

(A) Failure to explicitly refuse oral feeding, which allowed the judge to interpret her statement as applying only to tube feeding.

(B) An unenforceable request for euthanasia if she no longer recognized her family—a demand illegal in Canada at the time and alarming to authorities. She could have instead conditioned it: "If and when euthanasia becomes legal."

(C) No provisions to counter accusations that she had reversed her decision or to address the delays of protective service investigations.

(D) Lack of mechanisms making her refusal of assisted feeding irrevocable, regardless of others' interpretations of her behavior.

Lessons from her case

From this tragedy, three important points emerge:

(A) Even a single drafting mistake can render a directive ineffective.

(B) An otherwise sound directive may still fail if not paired with strategies to ensure enforcement.

(C) Flaws may result in immediate rejection or prolonged disputes; either way, they can prevent timely dying. The principles, "To delay is to deny" and "Justice delayed is justice denied" aptly apply here.

Directives function as patient decision aids, guiding individuals to consider future medical conditions and possible treatments, and to provide conditional consent for or against interventions. However, once flawed, those with authority can reject them, arguing that compliance would risk premature dying or conflict with the patient's "best interests." The result may be exactly what the patient sought to avoid—years of forced prolongation of life and suffering.

Type I flaws: Problems in the process of completing advance directives

1. Doesn't Allow Discriminating Refusal of Oral Nutrition = DADRON (0) [32]

The first task in advance care planning is deciding which directive to use. Standard advance directives rarely give patients the explicit option to request "Stop oral assisted feeding and hydration." For instance, the UK group Compassion in Dying provides an Advance Decision Pack with suggested language for declining treatments: "I understand life-sustaining treatment includes but is not limited to CPR, clinically assisted nutrition and hydration, artificial or mechanical ventilation and antibiotics for life-threatening infections." The pack

further cautions: "You cannot use an Advance Decision to refuse basic care that keeps you clean and comfortable" [33]. The problem is that some policymakers and clinicians categorize assisted feeding as a comfort measure.

The widely distributed Five Wishes form [34] goes further, embedding a subtly coercive clause. It obliges signers to accept: "I want to be offered food and fluids by mouth if it is safe for me to eat and drink. I want to be kept clean and warm." The form does not allow patients to reject only the first part ("offered food and fluids by mouth") while still retaining the second ("kept clean and warm"), which is universally desired. Unless the form is modified, it cannot help patients achieve the goal of avoiding a drawn-out dying process in late dementia. Though developed in the U.S., Five Wishes is distributed by more than 40,000 organizations across the globe, with over 40 million copies circulated. Families who rely on it may mistakenly believe it guarantees control over how and when they die.

Each of these documents could unintentionally lock patients into prolonged dying. By contrast, the C&C Tool [30] does give the option to end assisted feeding once any of seven listed conditions occurs. Yet it does not allow users to decline certain conditions selectively. For example, someone might still want feeding if they only need to be prompted to eat or persuaded to drink. Because the tool offers no way to make such distinctions, it risks triggering an undesired premature death.

2. Descriptions of Interventions and Conditions Not Understandable = DICNU (0)

The NY Directive [29] declares that it is designed for individuals in the earliest dementia stages. However, its readability is rated at grade-14 level [35, 36], far too complex for most people with early-stage dementia to comprehend. Critics of ceasing assisted feeding could claim that this makes the directive clinically invalid. Moreover, they could argue in court that the signer likely lacked true understanding of the document—opening the door to disregarding it on the grounds of inadequate comprehension, and thus exposing the patient to an unwanted or premature death.

3. Provides Inadequate Informed Consent = FIIC (8)

In response to the When Question, the NY Directive [29] defines "advanced Alzheimer's disease" as stages 6 or 7 of the Functional Assessment Staging Tool (FAST). However, it does not reference a specific version of FAST or include the corresponding criteria. (This article compares two such versions below.) The absence of detailed conditions means patients are not fully informed when they consent to cease assisted feeding in the future. This gap allows critics to argue that the directive requests conditional consent without adequate information—making it ethically questionable and risking premature dying.

4. Presents Other Conditions Inconsistently = FOCI (7)

When addressing the When Question, the online C&C Tool [30] produces a printable directive summarizing the planning principal's selections across 15 conditions. However, the tool also contains a secondary list of seven additional "informational" conditions. These appear only in a temporary pop-up window if the user chooses to click an optional link, and they are not carried over into the final printed document.

This design flaw opens two lines of criticism. If a planning principal reviewed the additional seven conditions, their treatment preferences are not fully captured in the printed directive, leaving it incomplete. Conversely, if the planning principal never opened the link, they were not adequately informed of all relevant options. In both cases, the directive falls short of ethical standards, giving opponents grounds to challenge it as inadequate. The result could be refusal to honor the directive, which may expose the patient to an unintended, premature death.

5. Doesn't Offer Workable Irrevocability = DOWI (0)

For directives to be reliable, they must be at least durable and ideally irrevocable. While several European nations legally recognize directives as binding, in day-to-day clinical practice they may still be disregarded. A 73-page Belgian analysis [37] illustrates this: in Austria, for instance, a directive loses validity if the patient "shows by his behavior that it is no longer valid." The problem is that such judgments depend on how a physician interprets behavior, which may diverge from the patient's original intent. In some jurisdictions, the threshold for revocation is surprisingly low. Estonia allows withdrawal by a person even "without capacity." In Finland, a higher level of capacity is required to draft a directive than to cancel it, effectively making cancellation easier. Hungary goes further, allowing revocation "regardless of the patient's disposing capacity."

The Netherlands gives clinicians broad discretion, permitting them to depart from a directive if they see "well-founded reasons" [37]. Since physicians themselves decide what counts as "well-founded," their interpretations may override the patient's stated wishes. While this can sometimes protect patients from harm, it

also risks undermining autonomy. For example, a directive might specify treatment refusal once the patient can no longer recognize family, yet opponents may argue it should not apply if the patient still appears calm or content [38]. Ignoring such nuances could result in premature death.

In the UK, doctors who disregard a valid directive may face civil liability for battery, but exemptions exist if they believe new circumstances justify ignoring it or if the patient shows behavior inconsistent with the directive. Again, physicians' discretion carries significant weight.

Some documents attempt to clarify how much flexibility should be given. The Dartmouth Dementia Directive, Version 32 [39] gave proxies and clinicians complete discretion, stating it was intended only as "guidance." Such vague language is unlikely to compel doctors to authorize the highly contested order to stop assisted feeding, which may result in prolonged dying. In contrast, Version 33 swung to the opposite extreme with a "Ulysses-type clause": instructions must be followed "no matter the current circumstances, and even if I express a different preference" later. Yet even this does not bind opponents, as directives are not contracts but unilateral requests. Similar approaches, such as in the SADD, amount to meta-requests that opponents can dismiss.

Thus, unless directives include additional safeguards to prevent revocation—either by physicians or by the individual's future cognitively impaired self—they risk being undermined. Without such measures, directives may fail to achieve their purpose and could result in extended, unwanted dying. More targeted strategies to strengthen irrevocability are discussed in Flaw #23, Undermining Proxies/Agents' Power.

6. Fails to Ask for Verbal Explanations = FAVE (2)

Dutch scholars studying clinical practice suggested that physicians' negative attitudes toward directives may stem partly from their limited participation in the advance care planning process [40, 41].

Improvement requires two key elements: active physician engagement and proper record-keeping.

The National Academy of Medicine's report Dying in America [42] criticized directives built around simple checkboxes, noting that ticking a box cannot capture the reasoning behind an individual's choices for future care. Ideally, patients' verbal explanations should be documented—sometimes through recorded interviews with a clinician. Such recordings can demonstrate the planning principal's mental capacity, careful thought, and independence in decision-making, while reducing suspicion that someone else filled out the form on their behalf. They also allow patients to explain personal motivations that may assist proxies or agents in convincing physicians to respect the directive. Moreover, these interviews can serve as evidence that the directive was signed willingly, without coercion, fraud, or undue influence [43].

Type II flaws concern the content of directives—specifically, the clinical situations and interventions chosen by the drafters and the way these are described.

7. Descriptions are Ambiguous, Vague, or Inconsistent = DAVI (3)

The case of Margaret Bentley illustrates the problem of ambiguity [14]. Her directive stated, "No nourishment or liquids." However, to prevent a prolonged dying process, she would have needed to clarify more precisely, for example, "Stop placing food or liquids in my mouth." A court ultimately interpreted her instruction as a refusal of tube feeding only, which unintentionally extended her dying.

Vagueness is exemplified by Barak Gaster's dementia directive, which declares, "I would not want any care that would keep me alive longer" [44]. The phrase "any care" is far too general to convince physicians to authorize the controversial order to cease assisted feeding, making it unlikely that the directive will be enforced, thereby risking an unnecessarily prolonged dying process.

In the Netherlands, euthanasia has been legally permitted since 2002 under the "Termination of Life on Request and Assisted Suicide Act," provided the physician meets the statutory "due care" requirements. The only criminal prosecution so far under this law offers a cautionary example [45]. In that case, a woman with advanced dementia had prepared and later revised her Advance Euthanasia Directive, but without sufficient professional guidance. Unfortunately, the document contained three potentially conflicting triggers: (1) "When I am admitted to a nursing home," (2) "When my quality of life has become poor," and (3) "When I consider the time is right for euthanasia."

Once admitted to a nursing home, she appeared content and cheerful, in contrast to her earlier fears of being condemned to the same kind of suffering endured by her mother with dementia. The treating geriatrician followed consultations with independent experts and discussions with the patient's family when interpreting the directive.

However, the physician presumed she lacked capacity rather than formally assessing it and therefore did not directly ask, "Do you want euthanasia now?"—a question to which she had previously answered, "Not yet." Moreover, the geriatrician ordered that a sedative be covertly placed in her coffee to reduce her resistance. This became known as the Dormicron case, after the brand name for midazolam (Versed).

The ensuing investigation and court proceedings spanned four years and ignited widespread legal and ethical debate. Six separate rulings, including two by the Dutch Supreme Court, ultimately followed. To reduce the likelihood of similar controversies, the Regional Euthanasia Committees (RTE) strengthened their protocols, requiring physicians to be more diligent and thorough prior to performing euthanasia. While existing rules already obliged physicians to evaluate decision-making capacity immediately beforehand, the RTE still did not mandate physician input during the drafting of directives or require formal review of completed directives for ambiguities, vague terms, or internal inconsistencies. If such safeguards had been present, this drawn-out and contentious case might have been avoided. Although the geriatrician was not penalized, questions remain about whether the patient's death occurred earlier than it should have.

8. Opponents Criticize Individual Conditions = OCIC (7)

The following examples highlight how critics may view specific elements of advance directives as problematic, suggesting that such conditions could prompt either premature death or unnecessarily prolonged dying.

Menzel and Chandler-Cramer's advance directive [46] (hereafter, Menzel) partially addresses the When Question with the condition: "When I…no longer demonstrate enthusiasm or joy in life activities." Critics may contend that this standard sets an unreasonably high threshold for patients with cognitive impairments, who often experience apathy, anhedonia, or depressive symptoms, yet still retain a desire to live. Requiring signs of enthusiasm or joy could thus be considered an inappropriate criterion, potentially accelerating death.

Similarly, opponents may challenge the three criteria in the C&C Tool [30] (and in the comparable directive from End of Life Washington [47]) as possibly leading to premature death:

(A) "I can no longer communicate with my loved ones through words." Critics note that many patients with advanced dementia can still communicate effectively via nonverbal means.

(B) "I no longer show interest in foods or liquids, and I have to be talked into eating or drinking." Caregivers' role is precisely to encourage intake, so this condition may not accurately reflect a patient's wish to live.

(C) "No interest in foods or liquids" based on nonverbal cues. Patients with Parkinson's disease or Lewy Body Dementia often exhibit masked facies, which can obscure expressions of emotion and interest, making this criterion potentially misleading.

The C&C Tool [30] also states: "If…I begin to experience delirium, agitation, or hallucinations, then I want my medical team to provide palliative sedation in order to avoid suffering until death occurs." Critics may focus on the words "begin" and "until death occurs," arguing that this directive could bias treatment toward hastening death. Additionally, since some causes of agitation are treatable, initiating palliative sedation without first attempting symptomatic management might risk premature death.

Opponents sometimes describe palliative sedation as a form of "slow euthanasia" [48]. One possible solution is respite sedation, which involves tapering sedative medications after a few days [49]. Once patients regain consciousness, they can reassess whether their suffering remains intolerable or if they wish to continue living consciously. Because this approach prioritizes relief from suffering rather than hastening death, it may be considered ethically acceptable by decision-makers.

9. Doesn't Insist on Severe Enough Suffering = DISES (3)

As discussed previously, the NY Directive [29] is limited because it fails to clearly inform planning principals about the specific conditions—the "If" criteria—that trigger the implementation of the directive. The NY Directive does not specify which version of the FAST scale should be used. If the Medical Care Corporation short version is applied for Stage 6 [50], the criteria include: patients requiring assistance with dressing, bathing, and toileting, and patients experiencing both urinary and fecal incontinence. Critics may argue that even if a patient meets all five of these clinical benchmarks, the level of suffering may not be intense enough to justify choosing death. If this argument holds, the directive could be deemed unacceptable, as it risks leading to premature death.

By contrast, Menzel's [46] directive avoids this issue. It explicitly identifies losses in memory and awareness, personality changes, and behavioral symptoms such as suspiciousness, delusions, hallucinations, or compulsive,

repetitive actions. It then requires that a majority of the clinical criteria from Stages 6 and 7 of the full FAST scale by Reisberg [51] be met, ensuring that the suffering threshold is more substantial before implementation.

10. Condition Reached; Is Still Content = CRISC (3)

The loss of the ability to recognize close friends and loved ones is often cited as one of the most feared consequences of advanced dementia. One directive, SADD [31], even uses this condition as its sole criterion. Critics may note that, even at this stage, patients may still experience enjoyment in the company of these familiar individuals, despite being unable to remember their names or explain familial relationships.

Overall, there is an important clinical distinction between simply reaching a particular stage or condition and assessing whether a specific condition causes sufficiently severe suffering. Some argue that using stages or conditions is necessary because advanced dementia patients cannot reliably communicate when their suffering reaches a level that would justify a desire to die. The counterpoint, however, is that these patients are equally unable to express that they still wish to live. As a result, directives that authorize death immediately upon reaching a stage or condition could be seen as ethically problematic, as they risk prematurely ending the life of a patient who might still desire to live. Authorities could interpret such directives as morally questionable, essentially imposing death on vulnerable individuals solely because they have lost communicative capacity.

11. Condition Reached; Is Possibly Treatable = CRIFT (5)

Agitated or violent patients may pose risks to themselves and others, and caring for them can be more resource-intensive. These behaviors are often driven by untreated somatic pain, severe confusion, or intense fear, especially when patients have no alternative means of expressing their suffering. Critics could argue that even when the exact cause of distress is unclear, it is clinically appropriate to first attempt an empirical trial of analgesics. If such treatment subsequently reduces disruptive behaviors without inducing excessive sedation, it suggests that the patient had been experiencing pain. Directives that bypass treatment trials are problematic because they may lead to premature death by failing to address potentially treatable sources of suffering.

12. Fallacy of Composition = FALCOM (0)

The “fallacy of composition” occurs when one wrongly assumes that a principle applying to a part automatically applies to the whole. Historically, this mistake has unintentionally shaped the Principle of Proportionality since Francisco de Vitoria’s 16th-century writings [52, 53]. De Vitoria reasoned that if feeding a patient produced severe discomfort or near-certain distress, withholding it would not constitute a mortal sin. Within Catholic ethics, stopping or avoiding treatments that are no longer suitable for a patient’s condition is acceptable, but deliberately intending death—even for compassionate motives like relieving irreversible suffering—is never morally permissible.

Daniel Sulmasy clarifies this distinction, noting that patients experience suffering as whole persons, and it is primarily the disease itself, rather than the treatment, that contributes to the genuine burden considered in proportionality decisions [54].

A contemporary example involves AMDA—The Society for Post-Acute and Long-Term Care Medicine [PALTC], representing over 5000 clinicians specializing in dementia and post-acute care [55]. In 2019, AMDA’s Resolution A19 recommended that all residents continue comfort feeding until observable distress occurs, irrespective of individual advance directives [56, 57]. By adopting this approach, which mirrors de Vitoria’s logic rather than Sulmasy’s holistic view, AMDA arguably risks prolonging the dying process.

13. Omits Conditions Often Dreaded = OCOD (4)

Advance directives may fail to address certain scenarios that individuals most wish to avoid, leaving gaps that can result in extended dying. When directives do not explicitly include feared conditions, patients who encounter these situations may experience prolonged suffering because the directive does not automatically guide care in those omitted circumstances.

Two Illustrative Examples: Religious and Humanistic

Daniel Sulmasy posed a thought-provoking question about a condition in which suffering is difficult to detect: "If a person, considered as a whole, exists in a state where conscious interaction with the physical world is absent, yet the individual is not dead and remains united with the One, True, and Eternal Source of all life and goodness—can this person be considered free from suffering?" [54] While Sulmasy framed this in a religious context, focusing on patients in a persistent vegetative state and their relationship with God, the principle can be applied to humanistic scenarios, particularly advanced dementia. Consider a patient with severe cognitive decline who

appears to be "just sitting there," seemingly unresponsive. The analogous question becomes:

"If a person, considered in their entirety, lacks the cognitive capacity to engage with others and therefore is deprived of all joy derived from human relationships—can this person be said not to be suffering?"

This second formulation highlights the profound existential suffering that arises when a patient's cognitive impairment severs meaningful relationships. Suffering is not confined to the patient alone; family members and caregivers also endure distress. Ignoring conditions that induce such suffering risks rendering advance directives ineffective and can unintentionally prolong the dying process.

Part Two: Common pitfalls in implementing completed directives for dementia patients

Completing a clear, detailed, and comprehensive advance directive is necessary, but it is not sufficient to ensure its effectiveness. Beyond drafting the directive, practical measures must be in place: interventions must be legally and ethically acceptable, physicians must be compelled to follow the orders, and safeguards must exist to prevent third parties from undermining them.

Case Example: Directive not honored

In 2013, Susan Saran, then a senior regulator at the Chicago Board Options Exchange, received a life-altering diagnosis: frontotemporal dementia. She was placed on disability and advised to settle into a supportive community before losing the ability to care for herself [58]. At 57, she retired and relocated to Kendal Senior Living Community in Ithaca, New York, purchasing a $500,000 residence where she intended to live out her remaining years. In 2018, she completed the NY Directive [29].

However, when Saran submitted her directive to Kendal administrators, they consulted legal counsel and refused to comply. Their refusal may have stemmed from a mistaken belief that the facility was obligated to provide oral feeding, even when a patient had clearly and legally documented a request to decline such intervention [59].

Reflecting on the experience, Saran said, "I didn't realize I was signing away my right to self-determination," and, "I was appalled that my future demented self takes precedence over my competent current self" [60]. Her sense of security—believing she had a plan in place—was shattered. Fortunately, authorities informed her before she lost decisional capacity, giving her the chance to pursue additional strategies or relocate. She ultimately chose the latter.

Type III flaws are inherent qualities of completed directives that make them ineffective or unacceptable

14. Intervention Not Clinically Effective = INCE (3)

Gaster's "dementia-directive" [44] includes the statement: "I would not want any care that would keep me alive longer" (original emphasis). While clear in intent, this intervention may fail in practice. Patients might have to wait years before developing a life-threatening illness that justifies agreement among caregivers to withhold treatment. During that interval, they could experience preventable suffering because treatments that alleviate symptoms and preserve life are avoided. As such, Gaster's directive may not reliably prevent prolonged dying.

15. Intervention Not Acceptable To Authorities = INATA (0)

The C&C Tool [30] lists one option as: "Keep me comfortable while stopping all treatments and withholding food and fluid so that I can die peacefully." Some opponents consider such directives unacceptable. As Rebecca Dresser notes, legal authorities might interpret the deliberate withholding of nutrition and hydration as closer to prohibited active euthanasia than to legally permissible withholding or withdrawal of life-sustaining treatment [61]. Clinically, if a physician or family member follows this directive, ambiguity arises regarding the cause of death: (A) it may result from withholding essential sustenance—potentially classified as euthanasia by omission—or (B) from the patient's severe cognitive decline, leaving her unable to recognize or ingest the food and fluid provided. Either scenario can culminate in death due to the underlying dementia.

A more widely acceptable alternative is to withdraw only assisted feeding while continuing to make food and fluid available within reach. This approach can help assess whether functional loss is genuinely irreversible and whether suffering persists. According to Brassington [62], "withdrawing life-sustaining treatment when death is not the intended outcome—and it may not be—is not euthanasia at all, passive or otherwise."

16. Limited Ability to Combine Conditions Causing Only Moderate Suffering = LACOMS (0)

Some directives may be dismissed if they list conditions that individually produce only moderate suffering, even

though planning principals may find these situations intolerable, especially when multiple moderate conditions occur simultaneously. Among the directives reviewed, only the C&C Tool [30] allows combining two or more specified conditions to justify ceasing assisted feeding.

Suffering may also extend to loved ones, who experience distress both from empathy for the patient and from the loss of meaningful interaction with them. For some planning principals, the combined weight of their own suffering and that of loved ones—even if each element is moderate—may be sufficient to desire death from the underlying disease. Yet, none of the directives examined here explicitly account for the suffering of family or caregivers.

17. Who is the Authority to Determine If It Is Time = WADIT (0)

Many traditional directives include three choices under the heading "To not prolong life." Because dementia patients are generally neither terminally ill nor deeply unconscious, they are often guided to follow a secular interpretation of the Catholic Principle of Proportionality [52, 53]: "If the likely risks and burdens of treatment would outweigh the expected benefits." This standard has been incorporated into the Uniform Healthcare Decisions Act [63] and adopted by numerous states [64].

However, the Principle of Proportionality does not identify who should have the power to judge whether the burdens of treatment surpass the benefits. Conflicts frequently arise: some family members may insist on continuing assisted feeding, hoping the patient might briefly regain lucidity to express parting words like, "I love you. Goodbye." Others may view this as selfish, arguing that it prolongs suffering for an improbable and minimal benefit. Without explicit guidance, disputes over who decides can compromise the directive, extend the dying process, and create tension among family members.

18. How Authority Determines If It Is Time = KADIT (0)

The Principle of Proportionality also provides no instructions for evaluating different types of benefits against different harms or burdens. For example, certain relatives may feel the patient's occasional smiles indicate life is still worthwhile. Others may emphasize that prolonging life in advanced dementia risks leaving memories of dependency and suffering, contradicting the patient's repeated wishes to avoid leaving such impressions. If no agreement is reached, the directive can become ineffective, potentially prolonging dying and failing to honor the patient's intent.

19. Format Incompatible with Physicians Orders = FIFO (7)

Confucius famously said, "He who chases two ducks catches neither." Most directives reviewed in this analysis (all but one) attempt to serve both planning principals and treating physicians using a single form. By trying to fulfill these two distinct purposes simultaneously, such directives risk satisfying neither effectively.

The first purpose is to educate planning principals, elicit their preferences, and document advance treatment decisions. This requires a patient-focused decision aid tailored to the needs of planning principals. The second purpose is to communicate these decisions to future treating physicians, enabling the creation of medical orders that accurately reflect the patient's end-of-life wishes. Physician-facing forms can include medical terminology and necessary complexity without compromising clarity.

Ronald Dworkin cautioned, "The greatest insult to the sanctity of life is indifference or laziness in the face of its complexity" [65]. Nevertheless, Gaster and his primary care colleagues opted for a single, simplified form for both audiences [44]. Motivated by frustration over incomplete directives, they assumed patients would comply more readily with a straightforward "dementia-directive" requiring just one box to be checked. This simplicity, however, can undermine the directive's effectiveness and risk prolonging dying.

The C&C Tool [30] improves on this approach by having planning principals complete an online questionnaire, which is then used to generate a printout for physicians. Despite this innovation, the C&C Tool is not fully compatible with the widely used POLST form [66], which contains actionable orders applicable across care settings and generally must be followed by healthcare providers [67]. POLST forms provide three treatment options: (A) Full treatment; (B) Selective or limited treatment aimed at restoring function while avoiding burdensome interventions such as ICU-level care; and (C) Comfort-focused treatment, permitting natural death. In contrast, the C&C Tool printout lists four treatment options, creating difficulty when translating these preferences into the three POLST categories. Additionally, three of the four options involve refusing life-sustaining treatments, leaving the form vulnerable to

criticism that it biases decisions toward earlier death, which can make the directive appear unacceptable.

Research led by Ferdinando Mirarchi highlights the importance of improving how emergency personnel and physicians interpret POLSTs and advance directives. His studies demonstrated that including a short video from the planning principal explaining which interventions are desired or refused increases accuracy [68, 69]. For individuals anticipating advanced dementia, a video could clarify the wish to cease assisted feeding and caution against initiating automatic interventions like IVs, which could unnecessarily extend dying.

Failure to include such clarifying videos can result in either premature or prolonged dying. While video documentation is not yet a standard of care, its omission constitutes a recognized flaw.

Type IV flaws fail to incorporate mechanisms that ensure treating physicians honor a patient's directive and prevent third parties from undermining these instructions.

20. Strategies to Compel Orders by Treating Physicians = SCOTF (0)

Under most state laws, physicians may legally refuse to follow a directive if they believe it "requires medically ineffective health care or care contrary to generally accepted medical standards" [70], or for "reasons of conscience" [71]. These allowances are defensible: the first protects patients, while the second safeguards the moral integrity of providers.

However, some physicians assume they understand a patient's "best interest" better than the planning principal, who carefully considered and documented their treatment preferences based on personal values. In some cases, physicians mistakenly equate the authority to issue medical orders (granted by their state medical board) with the authority to determine the content of those orders—power which no entity lawfully possesses. Legally and ethically, physicians are prohibited from making such decisions on behalf of patients.

Proxies or agents can cite the probate code stating: "A health care provider…providing care to a patient shall…comply with an individual health care instruction of the patient…to the same extent as if the decision had been made by the patient while having capacity" [72]. They may also consult legal or clinical experts to alert treating physicians that issuing orders inconsistent with the patient's known wishes can result in the loss of immunity, civil or criminal liability, and administrative sanctions.

If it remains easy for physicians to disregard conditional requests, such as discontinuing assisted feeding, patients risk experiencing unnecessarily prolonged dying.

21. Physicians Require Additional Clinical Criteria = FRACC (2)

In the absence of measures preventing health care providers from adding extra clinical prerequisites, directives may be altered in ways that do not reflect the planning principal's intended end-of-life choices. These additional conditions often stem from a provider's reluctance to participate in the irreversible decision of allowing a patient to die. While authorities mandating extra criteria may aim to avoid premature death, there is no conclusive evidence demonstrating that they understand the best interests of an incapacitated dementia patient better than the planning principal.

Four notable examples illustrate this issue:

(A) Menzel [46] posed a provocative ethical question: "If someone has a clear directive to withhold food and water at a certain stage, but at that stage still values life and wants to eat, should we actually withhold nourishment?" {Original emphasis.} The answer, "No," allowed Menzel to introduce his philosophical concept of a patient's ability to continue appreciating life. He explained that withholding food and fluids depends on two factors: whether the triggering conditions in the advance directive are met, and whether the patient's ongoing interest in survival is sufficiently diminished {Emphasis added.}

(B) AMDA's Policy Ah9 [56, 57] advised against implementing stopping eating and drinking (SED) via advance directives in patients who continue to accept food and fluids. Instead, they recommended "comfort feeding" for advanced dementia patients, provided the patient shows no signs of distress or refusal [56, 57]. The rationale was that enforcing SED could signal to patients that their current life is less meaningful and potentially shorten their lifespan.

(C) Ladislav Volicer *et al.* [73] added a specific criterion requiring physicians to delay acting on directives until patients cease requesting assisted feeding. Volicer aimed to address AMDA's policy, operating under the assumption that patients would naturally stop requesting feeding before experiencing harm or distress from the act.

(D) Walsh [74] argued that dementia fundamentally transforms cognition, making resulting preference changes morally significant and worthy of consideration

in medical decision-making. This perspective, Walsh suggested, should reduce reliance on advance directives for dementia patients. His argument has been used to justify withholding compliance with directives requesting cessation of assisted feeding. (This article does not evaluate whether Walsh's argument extends the framework proposed by Dresser [75], whom Walsh did not cite.)

Omitting strategies to prevent "Physicians Require Additional Clinical Criteria" can result in harm:

The following three semi-fictional scenarios illustrate potential consequences. Cases I and II compare a capacitated patient's right to contemporaneously choose Voluntarily Stopping Eating and Drinking (VSED) with a physician's refusal to honor a similar request made in advance by an incapacitated patient. Case III demonstrates how awareness that such refusals are likely can itself produce severe harm.

Case I: A 96-year-old woman, medically stable but living alone, feels lonely and disengaged from life. She has outlived her spouse and close friends, and her sensory impairments—loss of hearing and vision—further diminish her enjoyment of daily life. Seeking to express love for her children in a tax-efficient manner, she decides to end her life. Despite attempts by family and professionals to dissuade her, she chooses to die through VSED. Under California law since Bouvia [76], and U.S. law since Cruzan [6, 11], her physicians cannot impose their personal values, nor can they override her decision through tube or oral feeding. While she must demonstrate capacity in a clinical evaluation, she is not required to justify her motives. Because she retains capacity, her decision does not rely on an advance directive.

Case II: A planning principal thoughtfully created an advance directive designed to protect his lifelong critical interests, ensuring his life narrative could persist meaningfully even after losing capacity. His directive stated:

"I want my estate to fund my grandchildren's university education, assist them in starting businesses, and, above all, prevent 'medical bankruptcy' caused by my care [77]. Therefore, I request cessation of all life-sustaining treatments, including assisted feeding, when I am no longer able to enjoy life due to advanced dementia or terminal illness."

The treating physician, however, flatly refused to honor this directive, asserting: "Financial considerations should never determine the timing of death." She argued that the request violated generally accepted health care standards. By framing her personal values as professional norms rather than a conscience-based conflict, she had no obligation to transfer the patient to a willing provider.

Although well-intentioned, the physician's paternalistic decision disregarded the patient's explicit lifelong values, substituting her own judgment of his "best interest." This refusal inflicted tangible harm: his grandchildren lost the opportunity to attend preferred universities, had no funding to launch new businesses, and within three years, the family declared bankruptcy.

The patient suffered on two levels. First, he was denied the chance to protect his family from financial hardship. Second, the process left lasting negative associations with his illness, casting it as the source of severe family misfortune. (Even though the patient could not be aware of these consequences due to incapacity, society does not require consciousness of harm for the deceased [78] to acknowledge that harm occurred. Similarly, awareness is not a prerequisite for recognizing harm in individuals with advanced dementia.)

Case III: Upon being diagnosed with early-stage dementia, a patient thoroughly researched online resources, made several phone inquiries, and came to a distressing realization: he doubted that his future physicians would respect his advance directive and allow him to die on his own terms. This anxiety, which can be called "Dementia Fear," weighed on him daily. Even more concerning, he understood that delaying action could trap him in advanced dementia for many years. Although his cognitive decline was gradual at the time, he also feared that an acute incident—such as a severe infection, head trauma, or fall—might abruptly compromise his physical or mental abilities. If this occurred and required hospitalization or institutionalization, the restrictive environment could permanently remove his ability to hasten death.

Despite still finding joy in Dixieland jazz, international cuisine, and family moments with his children and grandchildren, he took deliberate steps to end his life. He obtained over-the-counter products to reduce thirst, requested a month's supply of anti-anxiety medication from his primary care physicians, and then engaged in Voluntarily Stopping Eating and Drinking (VSED). His son stayed with him, and he passed away peacefully.

Norman Cantor insightfully observed, "Undertaking self-deliverance at an early stage of dementia entails the hazard of cutting short an existence that is still enjoyable (and might continue to be so for some unknown period)" [79]. Consequently, failing to include strategies that

prevent Physicians from Requiring Additional Clinical Criteria (PRACC) can result in the tragic loss of years of reasonably good living. Essentially, this represents patient-driven premature dying triggered by anxiety over the possibility of prolonged decline.

The flaw Physicians Require Additional Clinical Criteria (PRACC) may conflict with the four fundamental principles of bioethics [80, 81]:

- Autonomy: Changing the advance directive's triggering conditions unilaterally for patients who can no longer provide informed consent, despite prior explicit instructions while competent, disregards the patient's right to self-determination.
- Beneficence: The inevitable decline of advanced dementia eventually eliminates the patient's ability to experience life. Extending the dying process without enhancing quality of life contravenes beneficence.
- Non-maleficence: Lengthening the dying process often increases suffering, particularly if unrecognized or untreated, thereby violating the principle of non-maleficence.
- Social justice: The financial and resource burden of caring for advanced dementia patients escalates as the potential benefit decreases. Allocating scarce medical resources in this way, rather than to patients who may gain more with less harm, breaches the principle of social justice.

22. Undermining Planning Principals' Authority = UFFA (6)

Critics of orders to stop assisted feeding often exploit a recurring ethical tension as a "conceptual wedge" to promote their own values. This long-standing dilemma, discussed by bioethicists for over thirty years [82], is referred to here as the "classic conflict." It arises when a physician implements an order to cease assisted feeding that reflects the prior wishes of the planning principal, but the now-incapacitated dementia patient signals a desire for food and drink—through gestures, grunts, or even verbal cues like "Gimme." These actions create a clash between respecting the patient's earlier instructions versus honoring their present expressions, thus generating the "classic conflict."

Opponents of stopping assisted feeding often leverage this conflict to assert greater influence. For instance, AMDA ethicists stated, "We either violate the entire concept of advance directive and practice an injustice against the person as they once were; or we refuse to feed our patient and practice an injustice against who they are now" [56, 57]. While it is true that no universally accepted solution exists for this dilemma, it does not justify AMDA's suggestion that their providers automatically serve as decision-makers in resolving the conflict. The repeated use of "we" in their argument comes across as both presumptuous and paternalistic.

A significant logical error underlies AMDA's advocacy for Policy A19: the fallacy of bifurcation. They presented the ethical issue as if only two choices existed, ignoring other possible solutions. Additionally, the ethicists fell into the extrapolation fallacy, intensifying the paternalistic tone of their recommendation. For example, they stated, "The Society affirms the right of all… residents to receive comfort feeding until their behavior indicates refusal or distress" [emphasis added], implying a blanket application without accommodating individual nuance.

To address these challenges, four strategies are proposed:

(A) Highlight that the "experts" are promoting a new clinical practice guideline without following a rigorous development process;

(B) Demonstrate how their guideline is flawed in logic or design;

(C) Show that the guideline conflicts with existing legal standards;

(D) Introduce an advance care planning strategy aimed at preventing the emergence of the "classic conflict," thereby nullifying the need for these debates.

(A) Avoiding a Rigorous Development Process for New Clinical Practice Guidelines

Currently, there is no known "dementia" directive that has undergone a thorough process of developing a new clinical practice guideline, which is defined as a structured method for translating the best available evidence into best practice through a logical sequence of key action statements, supported by explanatory text, evidence profiles, and graded recommendations linking actions to evidence [83, 84]. Developing such a guideline typically requires over a year and involves gathering input from healthcare professionals and patients through surveys and focus groups, as well as conducting pilot studies that are iteratively analyzed and refined.

Research on advance care planning for late-stage dementia remains in its infancy. For instance, Santulli *et al.* conducted six workshops with 170 participants, of whom only 40 completed a questionnaire and 27 indicated they would complete a dementia directive for themselves. There was no follow-up reported to

determine whether these individuals actually completed directives [85].

(B) Flaws in the Proposed Recommendations

Menzel's modifications to planning principals' directives [46] exhibit four critical shortcomings:

1. The directive fails to guide clinicians on how to determine, with sufficient medical certainty, whether a patient's desire to survive is "sufficiently low" to permit death.
2. It does not reference a validated scale or establish a cutoff score for assessment.
3. It leaves unspecified who is qualified to make such judgments, potentially allowing non-physicians to assume this role, as the issue extends beyond purely medical considerations.
4. Most concerning, Menzel permits an undefined third party to observe and interpret nonverbal patients' behaviors to assess whether they value their own lives. For example, he describes "Sheri," whose cognitive deficits prevent her from anticipating the value of survival, concluding that her continued existence "does not much matter to her now."

Many ethicists argue that it is morally unacceptable for one person to decide whether another person's life is worth living. Implementing such practices risks initiating a "slippery slope" that could culminate in serious humanitarian consequences [86].

Regarding Volicer's proposal [73], the challenge is determining the threshold of decisional capacity needed to honor a patient's requests for assistance with eating and drinking. Jaworska suggests that if people with dementia can demonstrate that they value experiences in their lives by explaining their choices, their current decisions should take precedence over prior directives [87]. The central question, then, is how minimal a behavioral standard satisfies Jaworska's requirement: is simply opening the mouth and swallowing adequate? Smiling when fed? Saying "Mmmm"? Those concerned for the patient's welfare may also need to weigh whether the patient has reached a stage they previously defined as causing intolerable suffering.

Walsh [74] and the 17 open-peer commentaries on his work did not fully integrate the goal of minimizing pain and suffering as a core personal value. Yet every competent adult in the U.S. retains the right [88] to avoid severe suffering, a claim that persists even after capacity is lost. Patients with advanced dementia are likely to endure more suffering than many providers realize, as they may be unable to communicate discomfort and care providers' perspectives on suffering are often limited. Furthermore, roughly 40% of patients diagnosed as being in a persistent vegetative state are misdiagnosed [89], indicating that many may indeed be capable of experiencing pain and distress.

(III) Protocols that Undermine Planning Principals' Authority (UFFA) may conflict with both the intent and explicit provisions of laws that restrict physicians from making treatment decisions on behalf of their patients. Four key points illustrate this:

(C.1.) In many legal jurisdictions, treating physicians are not permitted to act as proxies or agents for their patients. This restriction aims to prevent conflicts of interest by limiting the decision-making power of those providing care.

(C.2.) When a discrepancy arises between the instructions in a patient's advance directive and the guidance of a currently authorized proxy or agent, the patient's directive legally takes precedence over the physician's judgment of the patient's "best interest." For example, in Cynthia Cardoza v. Physicians [90], the plaintiff sued her mother's doctors for causing unnecessary suffering, denying the patient's right to die with dignity, and inflicting severe emotional distress. The physicians argued they were immune under California Probate Code §4740, claiming they followed the decisions of a person they believed had authority (the plaintiff's brother). However, the appeals court determined the physicians did not act in good faith because they knowingly ignored the patient's advance directive, administering life-sustaining treatment and performing surgery contrary to her stated wishes.

(C.3.) A semantic consideration: since advance directives take precedence over legally designated proxies or agents (via durable powers of attorney for healthcare), the directives themselves must be considered durable.

(C.4.) The Federal Patient Self-Determination Act of 1990 (PSDA) [9h] specifies that healthcare providers cannot condition care or discriminate based on whether a patient has executed an advance directive. Some interpret this law as prohibiting providers from refusing treatment solely because they disagree with a patient's treatment choices.

(IV) Strategy to Prevent the Classic Conflict

To address the flaw of Undermining Planning Principals' Authority (UPPA), strategies can be implemented to strengthen the authority of proxies and agents. This approach is discussed in the following section.

23. Undermining Proxies/Agents' Power = UFAF (5)

AMDA's Policy A19 [56, 57] does not direct physicians to fulfill their ethical and legal duty to consider the substituted judgment of proxies or agents. Instead, it advises:

"Although [our policy to refuse] may be an issue where common ground cannot be found with the health care proxy, the provider must engage with them and fully explain the rationale behind the choice to refuse to implement SED [stopping eating and drinking] by AD [advance directive]."

The emphasis on "engage" and "explain" signals that the policy anticipates resistance, reinforcing the difficulty of the situation. Changing physician behavior under this policy may require precedent-setting litigation or new legislation—both time-consuming and uncertain.

Professor Thaddeus Pope has suggested using an irrevocable Ulysses contract to address challenges like those experienced by Margaret Bentley [92]. This article offers specific strategic recommendations for overcoming this flaw.

Advance directives can provide planning principals with multiple options for deciding who determines whether to honor the patient's past versus present wishes:

(A) Future Treating Physician: This option may appear similar to AMDA's Policy A19 but differs ethically. It relies on the patient's voluntary trust in the physician to honor the directive, whereas A19 imposes this choice on incapacitated patients without consent. In A19, the breach of trust is exacerbated because providers are assumed to know that the directive's requests directly conflict with the patient's current condition.

(B) Future Demented Self (Volicer's Recommendation): This approach aligns with laws in many states allowing patients to receive life-sustaining treatment without capacity [93] and mirrors practices in several European countries where directives can be revoked regardless of capacity [37]. However, relying on the "future demented self" is a weak strategy because behavior at that stage is unpredictable, making it difficult to honor controversial directives.

(C) Proxy/Agent with Full Authority: Giving the proxy or agent complete discretion to act according to substituted judgment can be effective if two conditions are met: first, the proxy's instructions must accurately reflect the patient's wishes, which is often challenged due to the concordance problem; second, the proxy must convince future healthcare providers to follow these instructions, which may be contested or rejected unless supported by clear evidence. Additionally, the designated proxy may be unavailable, unwilling, or incapable when needed, and alternates may not be as trusted or effective. This option risks immediate failure or prolonged conflict.

(D) Strongest Strategy—Empowered Proxies/Agents: The most robust method to make directive requests effectively irrevocable is to legally empower proxies or agents to advocate for the directive. This involves two legal steps: first, the planning principal must waive the right to object to the proxy's instructions in the future; second, the principal must execute a separate bilateral contract with each proxy and alternate, obligating them to act as steadfast advocates to ensure the directive's requests are honored.

Note: Planning principals may assign other trusted individuals to participate in a bilateral "Ulysses contract," such as community leaders, religious or secular counselors, or specific relatives like attorneys or physicians. Although securing these additional signatures requires effort and time, this approach can help prevent the classic conflict from arising. If successful, opponents lose the ability to exploit the conflict as a "conceptual wedge" to impose extra clinical criteria on patients.

24. False Interpretation of Behavior Observed = FIBO (3)

This flaw is discussed last because it draws on previously presented examples, has wide applicability, and highlights the humility required to counter paternalistic assumptions. It occurs when strategies are absent that would stop physicians or others from assuming that an incapacitated patient's nonverbal actions reliably indicate their desires.

As Jongsma notes:

"Changes in behavior should not automatically be taken to reflect new values. The inability to confirm prior decisions, or actions that contradict what mattered to the person before, is part of the devastating decline caused by dementia and should not be interpreted as signaling consent to interventions" [94].

For instance, a patient might open her mouth passively to accept food, sometimes only after repeated encouragement. Misreading such behaviors can produce false positives or false negatives, though the frequency is unknown. These misinterpretations can lead to either premature or extended dying:

- False negative: The patient seems to reject food or fluids but truly wishes to continue living.

• False positive: The patient appears to want feeding continued but actually prefers to die naturally from the underlying illness.

Case A – Volicer's Criterion

• Observed behavior: Patient stops asking for assistance, remains silent or indifferent when food is offered.
• Assumed meaning: Patient wants to die.
• Action: Physician halts assisted feeding; patient dies.
• Reality: False negative. Dementia limits the patient's ability to communicate the desire to live.
• Conclusion: Misinterpretation caused premature death.

Case B – C&C tool, end of life Washington, AMDA A19

• Observed behavior: Patient turns head, clamps mouth, or spits out food.
• Assumed meaning: Patient wants to die.
• Action: Physician stops assisted feeding; patient dies.
• Reality: False negative. Refusal may stem from unrecognized pain (oral or gastrointestinal), not a wish to die.
• Conclusion: Misinterpretation resulted in premature death.

Case C–Cooperation during assisted feeding (Principle of proportionality and AMDA A19)

• Observed behavior: The patient passively cooperates with feeding, opening her mouth and swallowing the food offered.
• Assumed meaning: The patient desires to continue living.
• Action taken: The physician continues assisted feeding rather than following the patient's advance directive, which identified other sources of suffering. The patient must wait until her nonverbal signals during feeding are interpreted as distress.
• Reality: False Positive. The patient actually intends to die, having reached a stage she previously defined as causing intolerable suffering or placing burdens on her loved ones. Her apparent cooperation is a reflexive response to caregivers tapping her lips or chin, combined with habitual eating patterns. Cognitive decline due to dementia prevents her from recognizing the harmful consequences of continued feeding.
• Conclusion: Misreading the behavior results in prolonged dying and suffering, directly contradicting the patient's intentions that motivated the directive.

Case D–Active requests conflicting with directive (Classic conflict)

• Observed behavior: The patient, now incapacitated, gestures toward food and fluid, indicating a desire to eat, conflicting with her prior directive to stop assisted feeding at a stage of severe suffering.
• Assumed meaning: The patient has changed her mind and wishes to continue living. Her nonverbal behavior is interpreted as revoking the directive. Legal standards often favor life by not requiring capacity for requested life-sustaining treatments.
• Action taken: The physician orders resumption of assisted feeding, sustaining the patient's life.
• Reality: False Positive. The patient's intent remains to die, to avoid personal suffering and reduce the burden on her family. Her gestures may reflect confusion about why feeding had stopped, temporary thirst, or hunger from incomplete metabolic adaptation. Her lack of capacity prevents her from understanding the negative consequences of continued feeding.
• Conclusion: Misinterpretation extends dying and suffering, violating the patient's expressed wishes that prompted her directive.

Overall Conclusions – False Interpretation of Behavior Observed (FIBO):

Physicians cannot reliably base decisions about continuing or stopping assisted feeding solely on a patient's present observed behavior. Such misinterpretation can either cause premature death for patients who want to live or prolong suffering for those who intended to die to avoid severe personal suffering or reduce burdens on loved ones.

Two cases where advance directives succeeded in fulfilling patient's goals

The authors of this article maintain an optimistic view that patients can achieve their end-of-life objectives without enacting new legislation or pursuing legal action. Two real-life examples illustrate successful outcomes:

Case IV demonstrates a directive specific enough to be applied to a different disease.

Case IV: A 71-year-old Australian man created a directive that clearly instructed that he should not receive

assisted feeding—even if he appeared willing—if he met certain behavioral and functional criteria commonly seen in advanced dementia. Years later, he suffered a sudden stroke. Although he appeared cooperative with feeding, his wife insisted that he would want assisted feeding to stop, as his current condition matched the behavioral and functional criteria outlined in his "dementia directive," despite the differing diagnosis.

His physicians respected his directive and issued an order to discontinue assisted feeding, even though Victorian law treats requests to stop feeding as "a values directive…[that] can guide, but not mandate decisions," which permits clinicians to continue feeding despite such directives. The physicians followed the directive because it was based on specific behavioral and functional characteristics rather than the stage or diagnosis of a particular disease. Additionally, the surrogate's instruction—his wife's—aligned with the directive [95].

The treating physicians/authors also observed: "Had [this patient] been admitted to another healthcare facility in a different state, with differing ethical or religious perspectives, honoring his refusal of feeding might have been seen as unacceptable…[potentially] leading to conflict and significant distress for all involved." The laws in Victoria, hospital policies, and the physicians' ethical judgments were critical to this outcome. If any had been different, the outcome might not have been different.

Case V demonstrates how a directive can overcome initial physician opposition

In 2009, "Charles" established his living will via two recorded telephone interviews, which were saved on an audio CD. At the time, his physician assessed him as having decision-making capacity, even though he was in the early stages of dementia. When asked whether he would still want assisted feeding to stop if medical dehydration caused discomfort—so as to avoid prolonged dying in advanced dementia—he answered "Yes" both times and provided coherent reasoning.

Seven years later, Charles progressed to advanced dementia. His wife, acting as his legal proxy, arranged his admission to a hospice and requested that the attending physician implement the directive. The physician initially resisted, arguing that stopping assisted feeding would damage internal organs, be painful, and not serve Charles' best interest.

Following consultation with the physician who had guided Charles' advance care planning, his wife supplied multiple supporting documents: (1) a printed copy of the directive, detailing the behavioral and functional conditions Charles had deemed severe enough to justify allowing death; (2) the original physician's written confirmation that Charles had the capacity to make these decisions; (3) the audio recordings showing Charles' informed consent to discontinue assisted feeding even if discomfort occurred; (4) a copy of Ganzini's research [25], which indicated that medically supervised dehydration usually allows a "good" and "peaceful" death; and (5) an offer for the treating physician to speak directly with the original advance care planning physician.

Within two days, the physician agreed to follow Charles' wishes, stating he was convinced this reflected the patient's true intent. Charles died peacefully over nine days [96].

The editors reporting the case [97] noted: (A) while extensive documentation is uncommon for directives requesting cessation of eating and drinking, it is advisable; (B) nearly all elements of an ideal directive for stopping assisted feeding were present; (C) the case shows that such requests can gain wider acceptance; and (D) they posed the question of whether, when a directive is this clear and conditions are fully met, it should be considered the "standard of care."

Discussion

A measured reflection:

Ethical dilemmas in end-of-life care are rarely resolved with straightforward solutions. A patient's advance directive may specify that the occurrence of any condition previously judged to cause severe suffering should trigger the cessation of assisted feeding. However, consider a scenario in which a patient exhibits two seemingly contradictory states: (1) he no longer derives joy from interacting with family or friends, but (2) he continues to take pleasure in simple activities. For example, he may remain passive when relatives visit, yet if staff place headphones on him and play Dizzy Gillespie, he might sit up, smile, and hum along while pretending to drum with his utensils.

These dual observations create a tension: the first condition points toward stopping assisted feeding, whereas the second suggests continuing it. How should such a conflict be addressed? Should the treating physician make the ultimate existential decision alone? Should the current proxy or a group of alternates convene to determine what the patient would most likely have

wanted? Should they wait until a further condition arises that clearly signifies severe suffering? Or should they seek guidance from an ethics committee?

Viewed more broadly, could this type of scenario itself be considered a structural flaw in advance directives? If so, how might it be prevented? One approach is to allow the planning principal to indicate in advance how such conflicts should be resolved. Options could include: (1) "Always prioritize preserving life"; (2) "Always prioritize alleviating my suffering"; (3) "Follow the consensus judgment of my proxies or agents"; (4) "Request, then adhere to, recommendations from an ethics committee"; or (5) designate a specific individual, such as "My attorney, Bernie," to make the decision.

Related studies

Research examining families' perspectives on end-of-life care highlights the challenges of ensuring directives are respected. A Dutch study [98], possibly the first to specifically investigate relatives' views on peaceful dying, found that only around 50% of family members believed their loved one with dementia had experienced a death that could be considered peaceful. Neglect and lack of respect were the most frequently cited concerns, and these perceptions were associated with lower assessments of peaceful dying. Importantly, the study did not explore whether families viewed physicians' refusal to follow patients' directives as a serious form of neglect or disrespect.

In a separate German study, Schoene-Seifert *et al.* [99] asked participants if they would honor an advance directive stating: "If I lose my capability to reliably recognize my family…I do not wish to be treated by CPR, with ventilators, artificial feeding (IV or tube), or antibiotics in case of life-threatening infections (e.g., pneumonia)." The results revealed that 25% of respondents would not follow the directive regarding pneumonia treatment in late-stage dementia. When a "meta-directive" was added, requesting refusal of antibiotics even if the patient seemed content, 16.3% still refused, meaning that roughly two-thirds of participants would remain unwilling to comply.

These findings suggest avenues for further investigation, such as assessing whether people would honor directives requesting cessation of assisted feeding—a decision often viewed as more ethically contentious than refusing antibiotics—particularly when the criterion is "severe enough suffering" rather than inability to recognize family. Clearly, additional empirical work is required to understand these complex attitudes.

Even with a detailed directive, implementing advance care planning faces real-world barriers. For example, in Singapore, individuals newly diagnosed with early-stage dementia were far less likely than their caregivers to identify obstacles to advance care planning (10.5% versus 58%) [100].

Conclusion

This review concludes with three key points: the inherent limitations of the current literature; a reconsideration of paternalism as reflecting providers' self-interest rather than patient-centered care; and the broader societal responsibility to protect vulnerable, nonverbal, or incapacitated patients—a duty that extends beyond those living with advanced dementia.

Limitations of this review

This article began by noting that its critique would draw on three sources: the directives themselves, the authors' clinical experience, and reports from the literature. Empirical research is still needed to test the hypothesis that if directives avoid common flaws and incorporate additional strategies, physicians will be more likely to honor planning principals' end-of-life requests. To date, no study has compared the relative success of multiple directives in achieving patients' wishes for any end-stage condition.

In the absence of such research, philosophical reasoning suggests that planning principals may still benefit from investing effort in advance care planning. By clearly deciding which treatments they want or do not want, and communicating these choices to others, they engage in an inherently valuable activity—akin to Pascal's famous wager—regardless of whether the plan is ultimately followed. Completing advance care planning increases the likelihood of a timely death while reducing the risk of premature or prolonged dying, though it cannot guarantee outcomes. Still, planning principals can derive three key benefits: (A) satisfaction from knowing they took all reasonable steps to plan for the end of life; (B) confidence in their plan, which can alleviate the anxiety known as Dementia Fear and reduce the perceived need to orchestrate a hastened death; and (C) the reassurance offered to loved ones that the patient's wishes are known and a plan is in place that is likely to be effective.

Thoughtful, strategic advance care planning can thus contribute to a more peaceful experience for both planning principals and their families.

Not all paternalistic flaws are created equal

Paternalistic actions may be well-intentioned, self-serving, or even insulting. The flaw "Physicians Require Additional Clinical Criteria" (PRACC) illustrates this spectrum.

(A) Volicer's goal [73] is well-intentioned: he aims to benefit patients who appear to want to continue living and derive satisfaction from being fed. However, his approach may still be objectionable to those who prioritize autonomy, as it involves imposing treatment that patients did not explicitly request. Moreover, it may inadvertently prolong suffering for patients who have already reached a condition deemed to cause severe enough suffering.

(B) By contrast, a physician who refused to honor a directive for financial or personal reasons (Case II) can be seen as self-serving. Her decision, influenced by personal and professional values, used her authority to override the patient's wishes, resulting in significant harm to both the patient and the family.

(C) AMDA's Policy Ah9 [56, 57] exemplifies paternalism that is both self-serving and insulting. The policy assumes that directives are "influenced by prejudice that, strangely enough, may be exercised against one's future self," allowing providers to frame themselves as protectors of cognitively impaired patients and as heroes preventing their lives from being "wrongly shortened." Although AMDA's ethicists acknowledged that their refusal to implement SED via advance directive would likely cause shock and a sense of betrayal among families, their recommendation relied on an unproven allegation of patient prejudice. This combination of a seemingly enlightened perspective with rigid, harmful behavior reflects arrogance and inflexibility, highlighting the formidable challenges posed by such paternalistic practices.

The plight of incapacitated, nonverbal patients

When it comes to the enforceability of advance directives for patients with late-stage dementia, Thaddeus Pope observed that "technical legality diverges from practical enforceability" and emphasized that "there is a material difference between having a constitutional right and being able to exercise that right" [101]. Following the introduction of Policy A19, Jiska Cohen-Mansfield noted that granting individuals with dementia the right to die would require substantial adjustments in policy and practice, such as permitting cessation of feeding [102].

Looking ahead, legal reforms or judicial precedents could encourage malpractice insurers to educate physicians covered under their policies to act in alignment with AMA's Code of Ethics Opinion 2.20, which states: "The social commitment of the physician is to sustain life and to relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail" [21]. Until such systemic changes occur, individuals must take proactive steps in advance care planning: ensuring their requests are explicit and persuasive, eliminating potential flaws, and including strategies to address common obstacles.

The challenge extends beyond patients with advanced dementia. Society faces a broader question: Will it truly respect individuals' rights to express end-of-life preferences while failing to protect them from authorities who might impose their own values once those individuals become vulnerable, nonverbal, or incapacitated? If society allows those in power to override patients' autonomous choices—particularly under the pretext of preventing prolonged suffering for their "future demented selves"—this could set a dangerous precedent, potentially limiting self-determination for other vulnerable populations, including those who are medically healthy but socially or otherwise at risk.

Bioethics, as a discipline, addresses such conflicts that arise at the beginning and end of life. On June 24, 2022, the U.S. Supreme Court issued a ruling [103] permitting each state to enact laws banning abortion without exceptions. Despite differences in context, pro-choice advocates and end-of-life surrogate decision-makers share a core principle: both strongly champion self-determination. The critical difference, however, is that activists are typically united and vocal, while surrogates often feel isolated and powerless. A forthcoming article aims to address this disparity and explore strategies to empower surrogates in advocating for patients' wishes.

Appendix: Is pursuing legal action justified for patients with a flawed directive?

In 2020, the organization sponsoring SADD [31] provided free legal support to help proxies or agents achieve patients' end-of-life objectives. This effort likely

aimed to test the legal validity of the directive by seeking a court decision [104]. Such legal action may be triggered by physicians hesitant to honor directives requesting cessation of assisted feeding. A favorable court ruling could reassure physicians regarding the legality of their actions; however, a successful lawsuit would probably only make adherence permissible rather than mandatory. Judges cannot compel physicians to issue orders they fundamentally oppose, and physicians or institutions may always rely on conscientious objection clauses.

Moreover, legal challenges might fail because the SADD contains inherent flaws. Even a single flaw can give opponents sufficient justification to refuse compliance. The directive includes three major flaws, along with nine additional shortcomings, summarized as follows:

Major flaws:

(A) Doesn't Insist on Enough Suffering (DISES): Some patients may no longer recognize family or friends yet still wish to continue living to enjoy their presence.

(B) Intervention Not Acceptable to Authorities (INATA): The directive requests that "the scent of food not be present in my room," effectively withholding nutrition. Opponents may interpret this as euthanasia by omission, which could be considered illegal.

(C) Doesn't Offer Workable Irrevocability (DOWI): The addendum states that "nothing I do be deemed a revocation of this Advance Directive," but authorities may refuse to honor such a meta-request, especially without a bilateral Ulysses Contract.

Additional flaws include:

- Descriptions of Interventions and Conditions Not Understandable (DICNU): Written at a Grade 16 reading level.
- Fails to Ask for Verbal Explanations (FAVE).
- Condition Reached; Is Still Content (CRISC).
- Omits Conditions Often Dreaded (OCOD): Only one condition is addressed.
- Omits strategies to overcome key challenges:
  - Compelling Orders by Treating Physicians (SCOTP)
  - Physicians Requiring Additional Clinical Criteria (PRACC)
  - Undermining Planning Principals' Authority (UPPA)
  - Undermining Proxies/Agents' Power (UPAP)
- False Interpretation of Behavior Observed (FIBO): The supplement may misinterpret observed patient behavior.

Acknowledgments: None

Conflict of Interest: None

Financial Support: None

Ethics Statement: None

References

1. Alzheimer's Society. Over half of people fear dementia diagnosis, 62 per cent think it means "life is over." 2019. https://www.alzheimers.org.uk/news/2018-05-29/over-half-people-fear-dementia-diagnosis-62-cent- think-it-means-life-over. Accessed 23 Jan 2021.
2. Alzheimer's Association. 2018 Alzheimer's disease facts and figures. Alzheimer's & Dementia. 2018;14(3):367–429.
3. The Lewin Group Model (2015). Changing the trajectory of Alzheimer's disease: a national imperative. Appendix B. Current Trajectory. https://www.alz.org/media/documents/changing-the-trajectory-r.pdf Accessed 11 Sept. 2020. https://www.alz.org/documents_custom/Trajectory_Appendix_B.pdf (No longer accessible.)
4. Khachaturian, Z. Years of Alzheimer's Research Failure: Now what? Med- page Today (40). September 13, 2018. https://www.medpagetoday.com/neurology/alzheimersdisease/75075. Accessed 14 May 2022.
5. https://arstechnica.com/science/2021/06/a-disgraceful-decision-researchers-blast-fda-for-approving-alzheimers-drug/ Accessed 14 May 2022.
6. Merel SE, Gaster B. Advance directives for dementia can elicit prefer- ences to improve patient care. J Am Geriatr Soc. 2020;68(7):1606–8.
7. Merel SE, Gaster B. Response to Dr Sulmasy. J Am Geriatr Soc. 2020;68(7):1611.
8. Sulmasy DP. Why dementia-specific advance directives are a misguided idea. J Am Geriatr Soc. 2020;68(7):1603–5.
9. Sulmasy DP. We need more wisdom, not more paper: a reply to Merel and Gaster. J Am Geriatr Soc. 2020;68(7):1609–10.
10. Allecia J. Despite Advance Directive, Dementia Patient Denied Last Wish, Says Spouse. https://khn.org/news/despite-advance-directive-dementia-patient-denied-last-wish-says-spouse/

Accessed 04 Sept 2021.
11. Cruzan v. Director, Missouri Department of Health, 497 U.S. 261. 1990.
12. Cruzan v. Harmon, 760 SW 2d 408 - Mo: Supreme Court. 1988.
13. Ernecoff NC, Zimmerman S, Mitchell SL, Song MK, Lin FC, Wessell KL, Hanson LC. Concordance between goals of care and treatment decisions for persons with dementia. J Palliat Med. 2018;21(10):1442–7.
14. Bentley v. Maplewood Seniors Care Society, 2014 BCSC 165. http:// eol.law.dal.ca/wp-content/uploads/2014/02/Bentley-v.-Maplewood-Seniors-Care-Society-2014-BCSC-165.pdf Accessed 14 May 2022.
15. Fayerman, P. Margot Bentley dies, a finality that couldn't come too soon for anguished family, 2016. https://vancouversun.com/health/ seniors/margot-bentley-dies-a-finality-that-couldnt-come-too-soon-for-anguished-family. Accessed 04 Sept 2021.
16. Dening KH, Jones L, Sampson EL. Advance care planning for people with dementia: a review. Int Psychogeriatr. 2011;23(10):1535–51.
17. Dening KH, Jones L, Sampson EL. Preferences for end-of-life care: a nominal group study of people with dementia and their family carers. Palliat Med. 2013;27(5):409–17. https://doi.org/10.1177/0269216312464094.
18. Fagerlin A, Schneider CE. Enough: the failure of the living will. Hastings Cent Rep. 2004;34(2):30–42.
19. Hanson LC, Ersek M, Gilliam R, Carey TS. Oral feeding options for people with dementia: a systematic review. J Am Geriatr Soc. 2011;59(3):463–72.
20. Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, Volicer L, Givens JL, Hamel MB. The clinical course of advanced dementia. N Engl J Med. 2009;361(16):1529–38.
21. AMA Code of Ethics. Opinion 2.20—Withholding or Withdrawing Life-Sustaining Medical Treatment. https://journalofethics.ama-assn.org/article/ama-code-medical-ethics-opinions-care-end-life/2013-12 Accessed 04 Sept. 2021. (Also cited as: American Medical Association. "Opinion 2.20 Withholding or withdrawing life-sustaining medical treatment." Code of Medical Ethics (2014): 35–36.)
22. National Right to Life Council. http://www.nrlc.org/uploads/willt olive/California.pdf Accessed 04 Sept 2021.
23. Genova L. Still Alice. Simon and Schuster; 2009 Jan 6.
24. Davis DS. Alzheimer disease and pre-emptive suicide. J Med Ethics. 2014;40(8):543–9.
25. Ganzini L, Goy ER, Miller LL, Harvath TA, Jackson A, Delorit MA. Nurses' experiences with hospice patients who refuse food and fluids to hasten death. N Engl J Med. 2003;349(4):359–65.
26. Nevada S.B. 121. https://www.leg.state.nv.us/App/NELIS/REL/80th2019/Bill/6124/Text. At 10. Accessed 04 Sept 2021.
27. Pope TM. https://www.kevinmd.com/blog/2019/10/avoiding-late- stage-dementia-with-advance-directives-for-stopping-eating-and- drinking.html Accessed 04 Sept 2021.
28. Aleccia J. Should Hospitals Stop Spoon-Feeding Dementia Patients? 2017. https://www.beingpatient.com/dementia-end-of-life-directive/Accessed 04 Sept 2021.
29. End of Life Choices, New York. About the advance directive for receiving oral food and fluids in dementia. 2018. https://endoflifec hoicesny.org/wp-content/uploads/2018/03/3_24_18-Dementia-adv-dir-w-logo-no-donation-language.pdf Accessed 04 Sept 2021.
30. Compassion & Choices. Dementia Values & Priorities Tool. https:// values-tool.compassionandchoices.org/. Access 14 May 2022.
31. Final Exit Network. https://finalexitnetwork.org/supplemental-advance-directive-for-dementia/ (Not dated.) Accessed 04 Sept 2021.
32. https://www.acronymfinder.com/ Accessed 04 Sept 2021.
33. Compassion in Dying, Nov. 2021. https://compassionindying.org. uk/wp-content/uploads/2022/01/Advance-Decision-Pack-v2.2.pdf Accessed 17 Sept 2022.
34. The Five Wishes advance directive. https://agingwithdignity.org/ (Not dated.) Accessed 04 Sept. 2021.
35. Readability Formulas. http://www.readabilityformulas.com/freetests/ six-readability-formulas.php (Not dated.) Accessed 04 Sept 2021.

36. Mueller LA, Reid KI, Mueller PS. Readability of state-sponsored advance directive forms in the United States: a cross sectional study. BMC Med Ethics. 2010;11(1):1–6.
37. Nys H. with Raeymaekers P. Competence assessment and advance directives for people with dementia: ethical and legal aspects. June 2013. https://www.med.uio.no/helsam/tjenester/kunnskap/etikk- helsetjenesten/praksis/systematisk-etikkarbeid/competence-asses sment-and-advance-directives-for-people-with-dementia-ethical-and-legal-aspects.pdf. Also available from: WWW. kbs-frb.be. Accessed 12 May 2022.
38. Moratti S, Vezzoni C. Treatment directives in the Netherlands: the gap between legal regulation and medical practice. In: Self-Determination, Dignity and End-of-Life Care Brill Nijhoff. 2011. p. 287–298.
39. The Dartmouth Dementia Directive. https://sites.dartmouth.edu/ dementiadirective/ Accessed a more recent version (35) on 04 Sept 2021.
40. De Boer ME, Hertogh CM, Dröes RM, Jonker C, Eefsting JA. Advance directives in dementia: issues of validity and effectiveness. Int Psycho- geriatr. 2010;22(2):201–8.
41. Vezzoni C. The legal status and social practice of treatment directives in the Netherlands. (2005). (diss. Groningen RuG), Groningen: Rijksuniversiteit Groningen 2005, 199 p.
42. Institute of Medicine (US). Graphic, Palliative Care. "Dying in America: Improving quality and honoring individual preferences near the end of life." 2014. Or: Committee on Approaching Death: Addressing Key End- of-Life Issues. 2015. Dying in America: Improving quality and honoring individual preferences near the end of life. National Academies Press.
43. Witness statement of the California Hospital Association advance directive, for example. https://www.calhospital.org/sites/main/files/file-attac hments/form_3-1_-_english.pdf?1554912974 Accessed 04 Sept 2021.
44. Gaster B. An Advance Directive for Dementia: Documents that can guide care as dementia patients' minds gradually fade. Generations. 2019 Mar 2. https://dementia-directive.org/ Accessed 04 Sept 2021.
45. Buijsen M. Mutatis mutandis… On Euthanasia and Advanced Dementia in the Netherlands. Camb Q Healthc Ethics. 2022;31(1):40–53.
46. Menzel PT, Chandler-Cramer MC. Advance directives, dementia, and withholding food and water by mouth. Hastings Cent Rep. 2014;44(3):23–37.
47. End of Life Washington. My Instructions for Oral Feeding and Drinking. https://endoflifewa.org/wp-content/uploads/2020/10/My-Instructions-for-Oral-Feeding-and-Drinking-Combined-About-and-Document-Oct-2020.pdf Accessed 14 May 2022.
48. Billings JA, Block SD. Slow euthanasia. J Palliat Care. 1996;12(4):21–30.
49. Rousseau P. Palliative sedation in the control of refractory symptoms. J Palliat Med. 2005;8(1):10–2.
50. Medical Care Corporation. Functional Assessment Staging Test. https:// www.mccare.com/pdf/fast.pdf (Not dated.) Accessed 04 Sept 2021.
51. Reisberg B, Ferris SH, Franssen E. An ordinal functional assessment tool for Alzheimer's-type dementia. Psychiatr Serv. 1985;36(6):593–5.
52. Taboada P. Ordinary and Extraordinary Means of the Preservation of Life: The Teaching of Moral Tradition. 14th General Assembly of the Pontifical Academy for Life on the theme: Close by the Incurable Sick Person and the Dying: Scientific and Ethical Aspects, Vatican City. 2008 Feb 25.https://www.catholicculture.org/culture/library/view.cfm?recnum=8772 Accessed 04 Sept 2021.
53. Taboada P. The ethics of foregoing treatment at the end of life. https:// hospicecare.com/policy-and-ethics/ethical-issues/essays-and-articles- on-ethics-in-palliative-care/the-ethics-of-foregoing-treatment-at-the-end-of-life/ Accessed 04 Sept 2021.
54. Sulmasy DP. End-of-life care revisited. Heal Prog. 2006;87(4):50–6.
55. https://apex.paltc.org Accessed 07 Sept 2021.
56. Ethics Committee of AMDA. Resolution A19: Stopping Eating and Drinking by Advance Directives (SED by AD) in the ALF and PALTC Set- ting ("White Paper.") March, 2019. https://bit.ly/2VdDyV4 Accessed 04 Sept 2021.
57. Wright JL, Jaggard PM, Holahan T. Stopping eating and drinking by advance directives (SED by AD) in assisted living and nursing homes. J Am Med Dir Assoc. 2019;20(11):1362–6.
58. Aleccia J. https://www.washingtonpost.com/health/diagnosed-

with- dementia-she-documented-her-wishes-for-the-end-then-her-retirement-home-said-no/2020/01/17/cf63eeaa-3189-11ea-9313-6cba89b1b9fb_story.html 2020. Accessed 04 Sept 2021.
59. Pope TM. Whether, when, and how to honor advance VSED requests for end-stage dementia patients. Am J Bioeth. 2019;19(1):90–2.
60. Span P. One day your mind may fade. At least you'll have a plan. The New York Times. 2018 Jan 19;19. https://www.nytimes.com/2018/01/19/health/dementia-advance-directive.html. Accessed 04 Sept 2021.
61. Dresser R. Toward a humane death with dementia. Hastings Cent Rep. 2014;44(3):38–40.
62. Brassington I. What passive euthanasia is. BMC Med Ethics. 2020;21:1–3. https://doi.org/10.1186/s12910-020-00481-7.
63. Commissioners, Uniform Law. Uniform Health Care Decisions Act.
In Chicago: National Conference of Commissioners on Uniform State Laws. 1994.
64. For example: https://california.public.law/codes/ca_prob_code_secti on_4701
65. Dworkin R. Life's Dominion: An argument about abortion, euthanasia, and individual freedom. Vintage: 2011. May 11. (1994 edition, at 240.)
66. National POLST. POLST Program names.www.polst.org/program-names Accessed 04 Sept 2021.
67. National POLST Paradigm. National POLST Form. https://polst.org/wp-content/uploads/2019/10/2019.09.02-National-POLST-Form-with-Instr uctions.pdf Accessed 04 Sept 2021.
68. Mirarchi F, Cammarata C, Cooney TE, Juhasz K, Terman SA. TRIAD IX: Can a patient testimonial safely help ensure prehospital appropriate critical versus end-of-life care? J Patient Saf. 2021;17(6):458–66.
69. Mirarchi FL, Cooney TE, Venkat A, Wang D, Pope TM, Fant AL, Terman SA, Klauer KM, Williams-Murphy M, Gisondi MA, Clemency B. TRIAD VIII:
Nationwide multicenter evaluation to determine whether patient video testimonials can safely help ensure appropriate critical versus end-of- life care. J Patient Saf. 2017;13(2):51–61.
70. https://california.public.law/codes/ca_prob_code_section_4734
71. https://california.public.law/codes/ca_prob_code_section_4735
72. https://california.public.law/codes/ca_prob_code_section_4733
73. Volicer L, Pope TM, Steinberg KE. Assistance with eating and drinking only when requested can prevent living with advanced dementia. J Am Med Dir Assoc. 2019;20(11):1353–5.
74. Walsh E. Cognitive transformation, dementia, and the moral weight of advance directives. Am J Bioeth. 2020;20(8):54–64.
75. Dresser R. Dworkin on dementia: elegant theory, questionable policy. Hastings Cent Rep. 1995;25(6):32–8.
76. Bovier v. The Superior Court. http://people.brandeis.edu/~teuber/ bouvia.html. 58 N.J. 576; 179 Cal. App. 3d 1127; 225 Cal. Rptr. 297; 1986
Cal. App. Accessed 04 Sept 2021.
77. Mangan D. Medical Bills Are the Biggest Cause of US Bankruptcies: Study.2013. https://www.cnbc.com/id/100840148. Accessed 04 Sept 2021.
78. Smolensky KR. Rights of the dead. Hofstra Law Review. 2009;37(3):763–803.
79. Cantor NL. On avoiding deep dementia. Hastings Cent Rep. 2018;48(4):15–24.
80. Beauchamp TL, Childress JF. Principles of biomedical ethics. 4th ed. New York, Oxford: Oxford University Press; 1994.
81. Gillon R. Medical ethics: four principles plus attention to scope. BMJ. 1994;309(6948):184.
82. Dresser RS, Robertson JA. Quality of life and non-treatment decisions for incompetent patients: a critique of the orthodox approach. Law Med Health Care. 1989;17(3):234–44.
83. Rosenfeld RM, Shiffman RN, Robertson P. Clinical practice guideline development manual: a quality-driven approach for translating evidence into action. Otolaryngol Head Neck Surg. 2013;148(1_suppl):S1-55.
84. Shekelle P, Woolf S, Grimshaw JM, Schünemann HJ, Eccles MP. Developing clinical practice guidelines: reviewing, reporting, and publishing guidelines; updating guidelines; and the emerging issues of enhancing guideline implementability and

accounting for comorbid conditions in guideline development. Implement Sci. 2012;7(1):62.

85. Bunnell ME, Baranes SM, McLeish CH, Berry CE, Santulli RB. The dartmouth dementia directive: experience with a community-based workshop pilot of a novel dementia-specific advance directive. J Clin Ethics. 2020;31(2):126–35.
86. Sulmasy DP. An open letter to Norman Cantor regarding dementia and physician-assisted suicide. Hastings Cent Rep. 2018;48(4):28–30.
87. Jaworska A. Respecting the margins of agency: Alzheimer's patients and the capacity to value. Philos Public Aff. 1999;28(2):105–38.
88. Bradley A. Positive rights, negative rights and health care. J Med Ethics. 2010;36(12):838–41.
89. Andrews K, Murphy L, Munday R, Littlewood C. Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit. BMJ. 1996;313(7048):13–6.
90. Cardoza v. USC Univ. Hosp., No. B195092 (Cal. Ct. App. Aug. 13, 2008).
91. HR 5067. Patient Self-Determination Act of 1990. https://www.congress.gov/bill/101st-congress/house-bill/5067/text Accessed 04 Sept 2021.
92. Pope TM. Prospective autonomy and dementia: Ulysses contracts for VSED. J Bioethical Inquiry. 2015;12(3):389–94.
93. Pennsylvania Statute 5461(i)(2), at 160. https://law.justia.com/codes/pennsylvania/2016/title-20/chapter-54/section-5461 Accessed 2 Feb 2021.
94. Jongsma K. Losing Rather than choosing: a defense of advance directives in the context of dementia. Am J Bioeth. 2020;20(8):90–2.
95. Eastman P, Ko D, Le BH. Challenges in advance care planning: the interface between explicit instructional directives and palliative care. Medical Journal of Australia. Progressive 2020, 5; 9–11. Also: MJA Podcast: Associate Professor Brian Le Accessed 11 Sept 2020.
96. Terman, SA. Refusing Assisted Assistance with Oral Feeding: Conflict Over Patient's Best Interest. 145–150. In: Quill TE, Menzel PT, Pope TM, Schwarz JK. Voluntarily Stopping Eating and Drinking: A Compassion- ate, Widely-Available Option for Hastening Death. Oxford University Press; 2021.
97. Quill TE, Menzel PT, Pope TM, Schwarz JK. Voluntarily Stopping Eating and Drinking: A Compassionate, Widely-Available Option for Hastening Death. Oxford University Press; 2021. (Pope at p 225; Davis and Menzel at p 201; and Editors at p 150.)
98. Bolt SR, Verbeek L, Meijers JM, van der Steen JT. Families' experiences with end-of-life care in nursing homes and associations with dying peacefully with dementia. J Am Med Dir Assoc. 2019;20(3):268–72.
99. Schoene-Seifert B, Uerpmann AL, Gerß J, Herr D. Advance (meta-) directives for patients with dementia who appear content: learning from a nationwide survey. J Am Med Dir Assoc. 2016;17(4):294–9.
100. Ali N, Anthony P, Lim WS, Chong MS, Poon EW, Drury V, Chan M. Exploring differential perceptions and barriers to advance care planning in dementia among asian patient-caregiver dyads—a mixed-methods study. Int J Environ Res Public Health. 2021;18(13):7150.
101. Pope, TM. Legal Issues. Chapter 10. In: Voluntarily Stopping Eating and Drinking: A Compassionate, Widely-Available Option for Hastening Death. Oxford University Press; 2021 at 211.
102. Cohen-Mansfield J. The rights of persons with dementia and their meanings. J Am Med Dir Assoc. 2021;15(22):1381–5. https://doi.org/10.1016/j.jamda.2021.03.007.
103. Dobbs V. Jackson Women's Health Organization, No. 19–1392, 597 U.S. (2022).
104. https://www.thegooddeathsocietyblog.net/2020/06/07/comparing-dementia-advance-directives-part-3/ 2016;17(4):294–9.