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## Commentary

# New VSED Advance Directive — Progress, but Problems Persist

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**Abstract**

In their article, Pope and colleagues examine the ethical, legal, and practical complexities associated with the use of advance directives (ADs) to pursue voluntarily stopping eating and drinking (VSED) in the context of patients with advanced dementia. The authors detail the shortcomings of current VSED ADs, and they review a new VSED AD that they argue addresses these shortcomings and provides a better solution to the complexities associated with implementing VSED ADs. While the authors make a robust argument for the overall need and supportability of VSED ADs, this commentary highlights a problem that still persists even with the new VSED AD, specifically the absence of a robust ethical justification for continuing to honor the VSED AD even when the advanced dementia patient is requesting to eat or drink in the context of distress and suffering. Without this robust ethical justification, moral distress of family and caregivers is likely to occur, which could jeopardize the larger implementation of the VSED AD. Rather than pursue this more extreme measure without robust ethical justification, the commentary argues that the authors' alternative proposal of minimal comfort feeding is the more practical and ethical strategy that best balances the patient's longer- and shorter-term interests.

**Keywords:** VSED; advance directive; voluntarily stopping eating and drinking; dementia; advanced dementia

In their article, Pope and colleagues[1] examine the ethical, legal, and practical complexities associated with the use of advance directives (ADs) to pursue voluntarily stopping eating and drinking (VSED) in the context of patients with advanced dementia. These controversial forms of ADs are a response to not only the increasing prevalence of patients living with advanced dementia in the US,[2] but also the US's prohibition on medical assistance in dying for incapacitated patients, which creates a challenge for patients who do not desire to live the quality of life that advanced dementia entails. The authors then review a new VSED AD that they created, which they argue addresses the problems seen in the implementation of existing VSED ADs today. We applaud the authors' advocacy for this end-of-life option as a strategy to avoid preliminary employment of VSED, which the authors appropriately describe as "giving up good days to avoid bad years."

While we are sympathetic and in agreement with the authors' arguments for VSED ADs more generally — as well as their newly created version of the VSED AD that demonstrates improvements over other versions — we believe more is needed to establish the ethical justifiability and practicality of *always* honoring VSED ADs for advanced dementia patients, specifically when an advanced dementia patient requests to eat and drink. Pope and colleagues make an analogical argument with medical ADs and argue that for the same ethical reasons we should honor refusals of medical interventions in medical ADs, we should also honor commitments to VSED in ADs for advanced dementia patients. However, while this is plausible when patients are not explicitly requesting a previously refused medical intervention (or to eat and drink via a VSED AD), it is unclear whether this analogy also holds when patients are explicitly requesting to eat and drink, even if incapacitated.

As professional clinical ethicists, we regularly encounter complex ethical dilemmas involving honoring ADs when either the incapacitated patient or their family requests to override the AD.[3] For example, in some situations when an incapacitated patient requests a previously refused intervention — such as short-term intubation or feeding tube placement — clinicians sometimes justifiably honor their requests for treatment when it appears medically beneficial overall. The mere existence of an AD does not automatically preclude treatment when requested by the patient if doing so serves the patient's welfare and aligns with the duty of beneficence; context matters. This analogy is further challenged when considering the differing natures of the interventions in both examples. In medical ADs, treatment refusals serve not only longer-term interests (i.e., avoidance of a poor long-term quality of life) but oftentimes also more immediate, short-term interests to avoid the burdensome, harmful, or undignified nature of the intervention itself, whether that be dialysis, intubation, amputation, etc. The same is not necessarily true in the VSED AD example, which is focused exclusively on the longer-term interests of avoiding prolonging a poor quality of life with advanced dementia. Yet when considering eating and drinking on its own outside of longer-term quality of life interests, it is clear that eating and drinking can be a positive, beneficial, and even pleasurable act for the patient, especially when requested by the patient due to experiencing hunger and thirst. And given this, eating and drinking thus provides a palliative component that is also disanalogous to the medical AD analogy.

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Given these discrepancies, we advise the authors to further consider and explore how to address this apparent disanalogy. Our motivation for this request is not merely academic, but also practical. Many caregivers would be hesitant to withhold food and water from a patient with dementia who requests it, even if incapacitated. This would lead to substantial caregiver moral distress, and without robust ethical justification for why they *should* withhold food and water, caregivers' moral distress will likely endure and will jeopardize the likelihood that a VSED AD will be honored altogether, even when ethically appropriate to do so.

The authors may claim that the standard practice of honoring an incapacitated person's current request for previously refused treatment is *always* wrong if it contradicts an AD. However, we think that would likely be too radical of a shift in standard practice, as well as ignore the importance of understanding the contextual factors that underly each of these situations that may be ethically relevant. Alternatively, they may argue that the advanced dementia patient is relevantly different. If so, two possible routes are available to them, but each require substantive defense.

One route is to argue that advanced dementia patients who request food and water are more profoundly incapacitated than patients requesting beneficial short-term intubation or feeding tube placement after a stroke whose decisions or desires we would likely respect. If this is their claim, then they must show where that threshold is. Clearly, not all decisional incapacity is equivalent. For example, even if we do not typically think that a child's medical preferences are decisive, many think that they must be *at least considered* and given due weight.[4] Additionally, there may be an important difference between an incapacitated person's ability to refuse care versus their ability to request care, especially beneficial care.[5] For example, it is implausible that a request for pain medication requires the same cognitive decision-making capacity as a refusal of a life-saving intervention. The former presumably requires something as minimal as sensory perception and affect, whereas the latter requires foresight and reasoning.

Another related route is to claim that the advanced dementia patient is no longer a "person" in the morally relevant sense, whereas the other incapacitated patients still are. But if this is the authors' view, they bear the burden of providing a robust account of personhood and explaining why its loss justifies overriding current expressions of desire, even when those expressions concern basic care and comfort. They do engage with some of the literature regarding the moral authority of desires when discussing the *then-self, now-self* problem, but we think more should be said regarding their treatment of the connection between desire, values, and choices. In particular, there is an assumption that a request for food and water is always an expression of a "momentary desire." This very well might be true, but more needs to be said, especially when the request is persistent and coming from a place of physical or psychological distress from not eating and drinking. Why is the persistent request for food and water not part of a web of beliefs and desires that we might ordinarily take to be morally considerable? There may be a point at which the desire for food and water is fragmented from the rest of a person's beliefs and desires, but that would need to be spelled out in more detail.

Without an argument for one of these distinctions, the authors' position risks stipulating a difference without any principled reason for doing so. If we permit overriding ADs in some cases where patients lack decision-making capacity but express a current wish for beneficial treatment, we should in all cases unless there is a clear reason for not doing so. Again, this is particularly pressing given the required involvement of third parties who may experience significant moral distress when enabling VSED ADs, thus jeopardizing the likelihood of these important directives being followed altogether.

Interestingly, the authors mention a middle ground that many (include we as authors) would find to be reasonable, and that is the practice of minimal comfort feeding (MCF). Given the complexities raised above, MCF may be the best strategy to address this complex ethical dilemma. MCF uniquely respects the past critical interests that gave rise to the VSED AD by avoiding prolonged advanced dementia, while also respecting the patient's present wishes by avoiding distress associated with hunger and thirst.

While the authors' arguments are convincing regarding the overall benefits and appropriateness of the VSED AD, more is needed to ethically support refusing to acquiesce to an advanced dementia patient's request to eat and drink due solely to the presence of a VSED AD. We encourage the authors to continue to develop their arguments for their controversial position on addressing this dilemma, but in the interim, we believe their proposed middle ground approach of MCF remains the most ethically reasonable and justifiable option.

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