



MEDICAL ETHICS

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Stopping Eating and Drinking by Advance Directives: Choose Your Injustice

Jim, I have a hypothetical case for you. One of my residents with dementia, let's call him Bill, has an advance directive stating that when he no longer has meaningful social interaction, his caregivers should stop giving him food or water. He is now mostly mute, though rarely he may say a word or two. He still eats reasonably well and seems to enjoy mealtimes, occasionally saying "That's good" when eating ice cream. His agent with POAHC [power of attorney for health care] is his wife, Alice, who also has advanced dementia and can no longer function as his decision-maker but is more verbal than Bill. The two sit next to each other most of the day but seem to have little interaction. Bill's secondary agent is his son, Tom, who visits once or twice a month. Tom wanted the directive implemented, and after discussion with the attending physician an order for "No Feeding" was entered three days ago. Now the staff have to keep food away from Bill. He reaches for food from Alice's tray and seems to want it. Alice feeds Bill when the staff is not present, and he accepts it readily. On hearing this, Tom now wants Bill kept in his room alone during mealtimes, and he has asked the attending to prescribe a sedative to diminish Bill's desire or behavior to have food. The staff are concerned that Bill seems to want to be fed. They disagree with the plan of care now and are in some moral distress. Not surprisingly, Bill is declining day by day. How would you address this situation?

Thanks for asking, Pete! The Ethics Committee of AMDA — The Society

for Post-Acute and Long-Term Care Medicine submitted, and the House of Delegates adopted, a white paper about this very subject (*preview online <https://bit.ly/2VdDyV4>*). Stay tuned for a more thorough discussion, but here are the basic issues to consider.

Bill's advance directive is what we call SED by AD: Stopping Eating and Drinking by Advance Directive. Although these types of AD are relatively rare, they are increasing in prevalence. Generally they are made before or in the early stages of dementia, and they list the criteria that trigger an order to stop offering food and fluids. In Bill's case, the criteria involve social interaction. Some other SED by AD may list loss of ambulation, speech, continence, or recognition of family members among the criteria to stop feeding.

Make no mistake: This is not the more common Voluntarily Stopping Eating and Drinking (VSED). VSED is a well-studied, legal, and ethically valid way to end life. Often used in cases of cancer or intractable pain, VSED occurs when a competent individual voluntarily decides to stop eating and drinking. In these cases, our legal and medical ethics systems protect the individual from an invasion of his or her body with artificial forms of nutrition or forced feeding. Once you have determined a person has capacity, VSED is not an ethical challenge.

SED by AD, on the other hand, is always fraught with ethical, practical,

and legal problems, mainly due to what you are describing in this case: Bill is no longer *voluntarily* giving up eating and drinking. Rather, his proxy (and his AD) is imposing this decision upon him. Clearly, because Bill has to be isolated and sedated to prevent him from eating, this is not *voluntarily* stopping eating and drinking.

Your case, Pete, encompasses the ethical and practical issues of implementing SED by AD, but it also may present you with legal challenges. SED by AD is either illegal or restricted in almost half of all states. Check your state's legal code to make sure ("State Statutory Provisions Related to Orally Provided Food and Fluids and Comfort Care," July 2017; <https://bit.ly/2U7Vr7L>).

Let's look at the ethics issues involved here. We should start, as most ethics discussions do, with the principle of patient autonomy. Bill's AD is a tangible expression of how important a principle this is in modern medical practice. Patient autonomy is simply this: the person, or their proxy, gets to decide what is done to his or her body. But here's the rub: the Bill who wrote the AD would have wanted to end his life at this point. The Bill who is in your community seems to want to continue eating and living, even though he no longer seems to have meaningful social interactions.

We are bound by the ethical principle of autonomy to make sure that the patient's wishes are implemented. This, however, is a rare case where the decisions of the person for whom you're caring can be at odds with their AD, yet their proxy (Tom) is insisting that those previous wishes be implemented. Whose autonomy is more compelling here — the Bill who drew up the SED by AD, or the Bill who is actively seeking food in your community?

Many ethicists would doubt that the current Bill, with his advanced dementia, has enough cognitive ability to make autonomous decisions anyway. Just because he reaches for and enjoys ice cream does not mean that those principles upon which he based his AD — that life's value is found in meaningful interactions with others, based on his lifelong beliefs and values — have changed. So for many ethicists (and for some medical providers as well), the autonomy Bill possessed when drawing up his SED by AD is the overriding autonomy. They would advocate for isolating Bill during mealtimes, and perhaps even sedating Bill to extinguish food-seeking behavior and the discomfort and anxiety provoked by his hunger and thirst.

As important as autonomy is, though, I would propose that the ethical principle of justice is more important here. The principle of justice dictates that we treat our patients equally regardless of their economic status, sexual orientation, religion, race, or cognitive function. Bill, in his AD, made a judgment that his future self with advanced dementia would eventually be living a life that was of such low quality it should be ended. As his AD stated, this judgment was based on Bill's cognitive abilities — the ability to interact with others through conversation, reception of information, and comprehension of speech patterns and gestures. Although Bill has had a decline in his cognition, we should pause before we validate that as justification for ending a life.

Justice, the insistence that we treat all people equally, should act as a counter to the prevailing notion that life's value is dependent on cognitive ability, independence, and productivity. It should also act as a counter to the corollary that dependency and debility lessen a life's value. Justice asks us to pause and consider that the SED by AD drawn up by Bill before the onset of dementia may harbor a prejudice against dependency and dementia. By implementing it, we could be visiting that prejudice against Bill at a time when he is unable to advocate for himself.

The principle of justice also brings us back to the question of who has the overriding autonomy here, and whether Bill has enough cognition to make an autonomous decision anyway. Again, many ethicists place a higher value on decisions made by those who are cognitively intact, decisions that are informed by principles developed over a lifetime. As a result, decisions that are made regarding fleeting pleasures such as eating and drinking are of less value in determining the course of one's life. Although I certainly see the wisdom in this argument (I would not want my life determined solely by its appetites), justice asks us to question the assumption that those with advanced dementia have lost all agency and autonomy. To ignore Bill's actions in pursuing food is to say his current choices are no longer of value. To devalue his current choices is to devalue the person he is currently. Bill, with his advanced dementia, no longer has the advantage of basing decisions on the memory of who he was. He only possesses enough cognition to base his decision upon the present. Justice urges us to give value to decisions made

EDITOR'S NOTE

This case is not an ambiguous one. I think that in real life very few physicians would implement an order to withhold food and sedate someone who still appears to want food, can still feed himself, and is able to swallow safely like Bill in this vignette. That would probably be a criminal act. But it gets a lot more complicated when the person does not appear to desire food and is unable to put food or fluids into his own mouth, even when it is offered by being placed on a tray in front of him. And the situation becomes more complicated still when the person appears to be experiencing severe suffering in other ways or is having severe difficulties swallowing. We should not be placing value judgments on other people's quality of life, but there does come a point for almost everyone where the burdens of sustaining life — or as others might say, prolonging the dying process — outweigh any perceptible benefit beyond biological functioning. This is especially true when there is severe apparent suffering in a patient with profound dementia or in someone for whom virtually everything going into the mouth is going to wind up in the airway. Electing not to hand-feed selected patients under these circumstances when it is in accordance with their previously expressed wishes seems much less ethically fraught. We equate feeding with nurturance and love, but it may not always work out that way. Nursing homes will probably never be a place where SED by AD will be practicable or permissible, but other care settings may be. There will be much more discussion on this topic in the bioethics community and beyond, in the years to come.

— Karl Steinberg MD, CMD, HMDC,
editor in chief

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by everyone, regardless of their cognitive abilities.

Granted, there is no way to avoid an injustice here: you practice a great injustice against the previous Bill, who designed his SED by AD, if you refuse to implement it. You may also irreparably harm the relationship you've formed with Bill's family when you refuse to implement their wishes for their father. On the other hand, it would take a willfully blind provider not to see the injustice of isolating the current Bill from the rest of his community during mealtimes, taking food away from him when he has obtained it, and giving him lorazepam to dull his anxiety over removing one of the final enjoyments of his life — actions that would also violate your duty to non-maleficence, by the way.

In the end, one must choose to perform the injustice that seems to be of the least harm. I believe this is somewhat of a litmus test for each provider. Despite your daily involvement in the lives of those with cognitive and functional decline, do you agree that a life lived in dementia is of less value? Should you?

The Ethics Committee takes the position that the Society's members should refuse to implement SED by AD. It's a hard position to take, but one we see as the position that best protects our patients, even if we're protecting them from their own AD.

The Ethics Committee's now-adopted white paper takes the position that the Society's PALTC providers should refuse to implement SED by AD. We feel that if there is any organization that should recognize and validate the wishes of individuals with dementia, it should be the medical providers of our specialty. We do this in full knowledge that this may be seen as a betrayal by individuals who expect their AD to be followed and by the families who understand that patient autonomy is generally the overriding ethical principle guiding modern medical practice. It's a hard position to take, but one we see as the position that best protects our current patients, even if we're protecting them from their own AD.

I think the staff at your community, Pete, is right to question the current plan of care. It not only seems practically difficult, it seems downright cruel to Bill. I would advocate that you discuss this situation with the attending physician in order to cancel the "do not feed" order. Explain that it is the policy in your

community to offer food to all residents who actively seek it. At the same time, reassure the attending physician that you would never force food and fluids on Bill if he rejects them (again, look for our upcoming *JAMDA* article for guidelines on "comfort feeding" those with advanced dementia).

In addition, you should hold a meeting with the family, the attending physician, and the nursing staff to clarify your community's policy. This will involve a lot of tough discussions with the family

and may not resolve your differences over this situation, but you should use it as a time of growth for your community and an opportunity to develop policies that clearly defend the right of all residents to have access to nutrition and fluids if they so desire. 

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