

AMDA- THE SOCIETY FOR POST-ACUTE AND LONG-TERM CARE MEDICINE

RESOLUTION A19

SUBJECT: “STOPPING EATING AND DRINKING BY ADVANCE DIRECTIVES (SED BY AD) IN THE ALF AND PALTC SETTING”

INTRODUCED BY: ETHICS COMMITTEE

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Abstract:

The Ethics Committee of AMDA - The Society for Post-Acute and Long-Term Care Medicine (“The Society”) presents arguments for and against “Stopping Eating and Drinking by Advance Directives”. Although most conversations regarding SED by AD focus on patient autonomy, we refocus the discussion by including our obligation towards the ethical principles of justice, beneficence and non-maleficence as well. The Society is convinced that no choice can be made in implementing SED by AD without practicing an injustice: if one refuses to implement SED by AD, one violates the autonomy of the person who drew up the advance directive. If, on the other hand, one refuses food and fluid to a patient who still accepts food, one practices an injustice against that person as they are now. Recognizing that we have a greater responsibility to our current patients than to those who drew up the original advance directives, The Society recommends against implementing SED by AD in those patients who still accept food and fluids, implementing instead, a policy of comfort feeding for those with advanced dementia.

Introduction:

This paper examines the ethical issues surrounding “Stopping Eating and Drinking by Advance Directives” (SED by AD). SED by AD are directives made by a decisional adult instructing their caregivers to stop offering them food and fluids when they develop a certain degree of dementia. We will focus on two main ethical issues: patient autonomy and the duty to justice for our patients. We will also consider the practical issues involved in implementing SED by AD in the facility setting.

Voluntarily Stopping Eating and Drinking (VSED)

Voluntarily stopping eating and drinking (VSED) is a well-studied and legal method used by persons with terminal diseases to hasten death (Pope T. , 2011) (Pope & West, 2014). In VSED, a common practice is to initially stop eating and gradually taper off fluid intake. Death generally occurs within several days to two weeks after discontinuing fluids (Quill & Byock, 2000).

Stopping Eating and Drinking by Advance Directives (SED by AD)

In SED by AD, an individual will direct caregivers to discontinue food and fluids at a future time when he or she is no longer able to communicate his or her wishes and certain conditions are met. These instructions are typically included in written advance directives and may contain clauses such as “If I ever suffer irreversible central nervous system damage to the point that I do not recognize my family, I believe that it would be best for me to die [D]o not place food or water in my mouth. Instead, place it on my bed table. If I feed myself, I live another day; if I do not, I will die and that is fine.” (Pope T. , 2011)

Although the legality of VSED has been upheld in multiple jurisdictions as well as the Supreme Court of the United States, the withholding of food and fluids from someone who no longer has medical decision-making capacity is fraught with legal, practical and ethical complications. In fact, a 2017 review performed by the American Bar Association revealed that 21 states have statutes that limit its practice, while some states (such as New Hampshire and Wisconsin) ban the practice outright (American Bar Association Commission on Law and Aging, 2017). We recommend the reader review the statutes which effect SED by AD in their practice area. This paper seeks to address the ethical and practical issues that all providers should consider when counseling patients, families and staff regarding SED by AD.

Autonomy: the foundation of modern medical ethics:

In order to fully appreciate the ethical issues involved in SED by AD, it is important to understand that medical ethics in the United States developed as a reaction to the unchecked paternalism practiced by medical providers prior to the 1970s (The Tuskegee Syphilis Study, for example) (Center for Disease Control, 2016). The Belmont Report of 1978, one of the seminal documents of modern medical ethics, emphasized patient autonomy and informed consent as a foundational principle of any medical research with human subjects. Patient autonomy as a primary ethical principle was quickly adopted by the medical community along with three other principles: non-maleficence, beneficence and justice (famously detailed in Beauchamp and Childress’ book, *Principles of Biomedical Ethics* (Beauchamp & Childress, 2012)). As a result, the principle of autonomy, a person’s right to determine what is done to or with their body, is considered an inviolable right in modern medicine with few exceptions. One of the most concrete expressions of this autonomy is the advance directive. As the American Academy of Neurology Ethics and Humanities Subcommittee stated, “completing and following advance directives (in dementia) is desirable ethically because it permits a type of patient self-determination even in states of incompetence” (Berghmans, 2006). When patients are no longer able to express their views, the practitioner is guided by those wishes expressed in their advance directives. To violate those directives is anathema to most patients, families and facilities as well as healthcare providers.

Most discussions regarding SED by AD, then, begin and end with the principle of autonomy - when, if ever, should a provider violate the advance directives of someone with advanced dementia? A helpful exercise which serves to highlight the complexities of this is the hypothetical example of Margo, Sheri and Walter as detailed in the Hastings Center Report’s “Advance Directives, Dementia and Withholding Food and Water by Mouth” (Menzel & Chandler-Cramer, 2014). Margo, Sheri and Walter have all drawn up an SED by AD specifying that when certain criteria are met – when they no longer recognize family members, for example

– they wish their caregivers to stop offering them food and fluids. Assuming that all 3 have triggered the criteria of their advance directive, one must decide whose AD to honor. Margo is the one with the least advanced dementia - she appears to recognize people but does not use their names and does not differentiate one person from another, she continues to participate in art sessions and eats peanut butter and jelly sandwiches with obvious pleasure. Sheri has more advanced dementia - she is no longer able to walk or feed herself but maintains weight with feeding assistance during meals. She seems to enjoy the smoothies she is fed and coos when she holds a toy. Her use of language is minimal. Walter has the most advanced dementia – he recognizes no one and responds to no external stimuli such as touch or conversation. He requires significant encouragement to open his mouth and swallow when offered food. Unlike Margo and Sheri, he does not appear to derive any pleasure from his life in the long-term care facility. Of the three examples, whose advance directives do you honor?

In some ethicists' view, this choice hinges upon whether there is a difference between the “then-self” - that person who drew up the SED by AD - and the “now-self” - the person with advanced dementia who can no longer recall the reason they wanted their life shortened. The then-self expressed a desire to end their life if they forgot their family, or if they were no longer able to speak clearly, or if they no longer were able to walk. The now-self who has lost all of those abilities continues to reach for food, to show obvious enjoyment when eating and appears to actively participate in the life of the community. The family, facility and provider must now determine to whom they feel obligated – to the then self and their advance directives, or the current desires of the now-self? Legal scholar and ethicist Nancy Rhoden emphasized the importance of continuity between the “then self” and the “now self”. In her article, “The Limits of Legal Objectivity”, she reasoned that “someone who makes a prior directive sees herself as the unified subject of a human life. She sees her concern for her body, her goals, or her family as transcending her incapacity. It is at least one, if not an overriding, component of treating persons with respect that we view them as they view themselves. If we are to do this, we must not ignore their prior choices and values” (Rhoden, 1990). Ethicists such as Rhoden suggest that to ignore a person’s advance directives in favor of the now-self’s current desires is to treat the now-self as if they never had any previous notions or convictions about the source of life’s value and meaning. Many ethicists, citing this continuity, doubt that there should be any distinction between a “then-self” and a “now-self” with advance directives speaking for both the person who wrote them and the person with advanced dementia.

At the far end of the spectrum of honoring SED by AD, ethicist Ronald Dworkin advocates for honoring SED by AD in all cases, ignoring any assumed wishes of the person with dementia. He suggests that to substitute our judgment of what is best for a patient after they have lost capacity is to exercise exactly the paternalism against which their AD was meant to protect (Dworkin, 1993, pp. 201-231). Dworkin differentiates between “critical interests” – those convictions which define the overall value of one’s life versus “experiential interests” - those experiences which make life pleasant in the moment. Dworkin notes that critical interests (those interests which informed a person’s advance directives) should always hold sway (Dworkin, 1993, p. 201). Dworkin is part of a cohort of ethicists who feel that the simple act of eating, such as seen in the example of Margo and Sheri, could easily be reflexive rather than an indication of

an existential reorientation about the value of life. The question becomes not whether someone enjoys eating, but whether the consent to accept food and fluids in advanced dementia constitutes a relevant change of mind regarding the value and quality of one's life (Menzel, 2017).

Like Ronald Dworkin, would you implement the ADs of Margo, Sheri and Walter, or would you use a kind of sliding scale (suggested by Menzel and Chandler-Cramer), implementing their advance directives only when the subjective value of the person's current experience is sufficiently low (for example, honoring SED by AD for Walter, but for Margo and Sheri say "not yet")?

What about Justice?

As stated previously, the conversation regarding SED by AD usually focuses exclusively on the issue of autonomy. The ethics committee of The Society believes it would be a mistake to ignore other ethical principles here: autonomy, by its very nature tends to focus only on the decisions made by autonomous individuals, the "then-self" or their surrogate, rather than any preferences displayed by those who have lost capacity.

In order to address this issue with the interests of our (current) patients in mind, the ethics committee of The Society recommends that we do not forget our obligation to the ethical principle of justice. We are convinced that indeed, there is no decision that can be made in this situation that does not involve practicing an injustice of some sort. To ignore an advance directive is to practice an injustice against the person who, prior to developing dementia, expressed their deeply seated notions (their "critical interests") about how they would like to spend their last years, how they would like to be remembered and how they would like to spare their families the burdens of care involved in late stage dementia. On the other hand, it is hard to deny that stopping food and fluid to someone like Margo would represent an injustice done to a sentient human who has her own ideas (her "experiential interests") about what constitutes a life worth living. The principle of justice reminds us that when we give care to another human being, we must try to decrease the influence of any extrinsic factors - finances, religion, race - that would influence the care we give. It ensures that as healthcare providers, especially as providers for underserved and marginalized populations such as the elderly and those with dementia, our care will be influenced as little as possible by our and our culture's ageism. It also alerts us to the possibility that SED by AD can be an instrument of that ageism.

The Problem of Ageism:

Our society holds a prejudice against the elderly (Nelson, 2005). We cannot ignore the very real expression of this as manifested in the chronic underfunding of long-term care (American Healthcare Association, 2017). We also cannot ignore the influence of our culture which insists that life lived in independence is of more value than life lived in a long-term care facility. To approach our patient population with the equity each person deserves means to allow our decisions to be influenced as little as possible by our culture's prejudices.

Although one would hope that as those entrusted with the health of these elders, providers would demonstrate freedom from ageism, studies show that health providers, as a group, can display attitudes and approaches towards the elderly that tend to infantilize and marginalize them (Nelson, 2005). This should give one pause before implementing SED by AD. If the treatment of our patients is to be influenced as little as possible by prejudice against race,

sex, economics or religious preferences, it should also be influenced as little as possible by prejudice against age and dementia, a prejudice that, strangely enough, may be exercised against one's future self through one's advance directives. Providers should at least pause to consider whether an advance directive could be an expression of a person's fear and distaste of dependency and cognitive decline. Could the advance directive we are being asked to implement be an expression of prejudice against those with dementia and dependency? If so, even if the prejudice was expressed against one's self, do we countenance it and take part in it by implementing SED by AD?

If we allow the ethical discussion to only revolve around the issue of autonomy and the right of a person to determine their future, then the decisions we make as caregivers will always favor those with capacity, with the ability to understand their situation and express their preferences clearly regarding their care. Many providers will never have the pleasure of knowing their patients when they were decisional. We will not know Margo when she was able to drive to the shore to paint her landscapes; we won't know Sheri when she was a busy pediatrician, and we won't know Walter when he was a provider for his family of five. What we will know, intimately, is Margo, Sheri and Walter as they are now. If, as Dworkin suggests, we only allow their critical interests to determine our care, we risk practicing a prejudice in favor of those that live and think independently. To say that critical interests are more valid than the experiential interests of our patients is to devalue the daily experience of those with dementia. We not only show our patients that their current existence is less meaningful, we shorten their lives because of it when we implement SED by AD. If we simply focus on autonomy, we will inevitably leave our patients out of the decision-making process. It is the position of The Society that the care of our patients should always be informed by their current experiential interests. This is not to say that we entirely reject the expressed opinions of the person prior to the onset of dementia, but we must give at least equal weight to the current wishes, the experiential interests, of those people under our care in order to satisfy our duty to treat all people equally without regard to cognitive ability.

Choose your injustice:

Clearly, this is a decision fraught with conflicting emotions, especially on the part of the patient's family and health care proxy. To refuse to implement an advance directive that was designed to protect an individual from advanced dementia is a grave injustice and must be recognized as such. The refusal to implement SED by AD will no doubt be met with shock and a sense of betrayal by the family, and appropriately so.

But we remind our fellow Society members that in this situation, the provider is not being asked to choose between what is clearly right and what is clearly wrong, but rather to choose between two injustices. We either violate the entire concept of advance directives 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. The provider must recognize this and then choose the injustice that does the least harm. We are convinced that the greater injustice is that of ending the life of a person who wishes to continue to eat and drink and live. Although this may be an issue where common ground cannot be found with the healthcare proxy, the provider must engage with them and fully explain the rationale behind the choice to refuse to implement SED by AD. Some of the following practical issues may help in doing so.

Implementing SED by AD in the facility setting - practical issues

The oral intake of residents who survive to the most advanced stages of dementia typically declines in the last 6-12 months of life. Hanson et al. reported that residents with 3 months of weight loss had a 19.2% chance of dying over the following 3 months (Hanson, Ersek, Lin, & Carey, 2013). Given long enough, then, all patients with dementia die as a result of SED if they don't succumb to another illness sooner. SED by AD is essentially an intervention at an earlier point in this inevitable process of decline.

In order to implement this earlier intervention, though, health care professionals and facilities are presented with several practical challenges. Rather than being tasked with their typical role of ensuring adequate intake, staff would be tasked with the exact opposite: in those residents who can actively seek food, they would be asked to prevent access to it. Visitors and other residents may not understand the care plan and offer the resident food. All facility staff, from administration to environmental services as well as the other residents and all visitors would have to be enlisted in maintaining the non-feeding plan. This attempt to contravene many of the normal patterns of work and community in the facility setting could result in a morass of practical, ethical and legal difficulties.

Implementing SED by AD in the facility setting – violating the principles of beneficence and non-maleficence

Although those who draw up an SED by AD would assert that the most beneficent approach to their future dementia-influenced self would be to help them to end their lives, we demur. Referring to the practical implications of implementing SED by AD above, a request to prohibit access to food might require a resident to be sequestered in their room multiple times daily. Residents with dementia can experience benefits other than nutrition from the mealtime experience, including socialization (Keller, Martin, Dupuis, Reimer, & Genoe, 2015). As those with dementia lose their connections to the past, socialization with those around them provide their only anchor to reality in an existence filled with loneliness and anxiety. To remove them from the community at such a time should be viewed not only as a violation of our duty to beneficence, but as an act of outright cruelty.

In regard to our duty to non-maleficence, implementing SED by AD can present us with a need to prescribe medications to alleviate suffering not caused by a medical condition, but rather by an advance directive. Legal scholar Norman Cantor has written about his own SED by AD in a recent Hastings Center Report. In it, he states “If I appear receptive to eating and drinking (show signs of enjoyment or positive anticipation), so that I would be agitated or upset by non-feeding, I authorize sedation to relieve that upset...” (Cantor, 2018). The administration of medications to ease the suffering involved in end stage dementia is an expected standard of care for all Society members. In this example, however, we are asked to administer medications to extinguish a set of symptoms manufactured by a legal document. It directs the practitioner to prescribe medication, not to treat a disease, but to extinguish a normal positive experience, i.e., the enjoyment of eating and drinking. The use proposed by Cantor aims to extinguish one of the few pleasurable experiences our patient may have left. To us, this seems to violate the duty towards non-maleficence, to do no harm to those entrusted to our care.

Comfort Feeding:

In recognition, then, of the ethical and practical challenges involved in implementing SED by AD in the facility setting, the society recommends instead a policy of comfort feeding for all residents with advanced dementia (Palecek, et al., 2010). Rather than maintaining nutrition, the chief aim of comfort feeding is to provide pleasure in the taste, smell and texture of food as well as the great benefits of human interaction and shared experience around the daily rhythm of meal times. This involves offering hand feeding as long as the resident is not showing signs of distress and stopping the practice if distress or refusal develops. This approach can serve the needs of residents as well as honoring their receptivity or refusal of feeding. There should be no forced feeding of persons with advanced dementia, nor should there be forced non-feeding.

Staff members who administer spoon-feeding to residents should be trained and competent in safe and appropriate feeding procedures. Resident comfort and signs of resident distress should be observed closely and continuously during all feeding sessions. Food or water should be offered only if the resident shows receptivity and there are no signs of pocketing of food, or distress such as choking, coughing, or respiratory difficulty. Staff should avoid the use of any force to place food or liquid in a resident's mouth.

Comfort feeding at mealtimes in long term care, even if only a spoonful or a few sips of liquid, provides a setting in which social interaction can occur (Keller, Martin, Dupuis, Reimer, & Genoe, 2015). Although comfort feeding would benefit from further study, others have also advocated its use on the basis of quality of life, palliative care principles, and relational benefits (Morrison & Wu, 2019). Some research into various handfeeding techniques in dementia has been done and suggests improved intake and reduced adverse feeding behaviors when direct hand and under hand feeding techniques are used (Batchelor-Murphy, McConnell, Amella, & Anderson, 2017).

Typically, as the resident loses more weight, oral intake continues to diminish to perhaps only a few spoonfuls or sips at each meal. Eventually the resident completely stops receiving what is offered orally. At this point the resident will usually succumb within a couple of weeks. Families should be reassured that no force-feeding will occur and that all appropriate efforts will be directed toward resident comfort in the final phase of dying. Proactive hospice care can be helpful in managing the symptoms, if any, in this final stage of active dying, such as delirium, xerostomia, or abdominal pain.

Ideally, good advance care planning (ACP) will have anticipated this process and a discussion held with the healthcare proxy to clarify the chosen level of care. Many will find a DNR order and a Do Not Hospitalize or "comfort care" order to be the most appropriate plan. Hospice involvement may be essential for many residents.

As part of the ACP process, it may be helpful to use a POLST paradigm or similar document such as the MOST or POST. The issue of feeding should be addressed in ACP discussions. The "Comfort Feeding Only" model can be very helpful in these talks. Families should be assured that their loved one will be offered food and water at each meal only up to the point when they refuse or are unable to receive further feeding. Each meal will end when such signs occur.

Summary:

In summary, The Society recommends adopting a policy of comfort feeding for all nursing and assisted living facility residents with advanced dementia, despite any advance directives to the contrary. The Society affirms the right of all PALTC residents to receive comfort feeding until their behavior indicates refusal or distress. We base this on our ongoing commitment towards the value of life of those who live with advanced dementia and as a response to the ageism inherent in the assumption that a life lived in dependency is of less value. We reject the notion that critical interests should be given more weight than experiential interests on the same grounds. We also reject strategies to isolate residents with dementia in order to limit their access to food as we do the request to prescribe sedating medications for the purpose of extinguishing the desire to eat. In addition, we insist that the staff in the facilities in which we work should never be compelled to restrict a person's access to food, a basic right for every human no matter how dependent or challenged with dementia.

Furthermore, The Society encourages the development of policies in PALTC facilities to implement the above as well as ongoing training of staff in the safe and effective administration of comfort feeding and training of health care providers in providing end of life care and effective advance care planning discussions.

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