AMERICAN NURSES ASSOCIATION

ANA Position Statement (Draft for Public Comment)

Nutrition and Hydration at the End of Life[1]

Purpose

The purpose of this position statement is two-fold. The first is to clarify nurses' roles in the care of patients at the end of life, for whom decisions regarding artificial nutrition and hydration are being considered. End of Life is defined as "a final period (hours, days, weeks, months) in a person's life, in which it is medically obvious that death is imminent, or a terminal moribund state cannot be prevented" (Free Medical Dictionary, "end-of-life,". http://medical-dictionary.thefreedictionary.com/end+of+life, accessed Nov. 30, 2016). The second is to explain how nurses can work with other providers and with surrogate decision makers who are representing the patient's preferences and who have the patient's best interests at heart, as the surrogates consider the risks and benefits, and alternatives to various forms of nutrition and hydration for patients who are dying. These considerations apply to decisions to forgo food and fluids, dietary supplements and/or artificially administered nutrition and hydration.

Statement of ANA position

Adults with decision making capacity, and surrogate decision makers for patients who lack capacity, who have received adequate information and who are free from all forms of coercion, are in the best position to weigh the benefits and burdens of nutrition and hydration at the end of life, in collaboration with the health care team. The acceptance, modification, or refusal of clinically appropriate food and fluids, whether delivered by oral or artificial means must be respected, provided the decision is based on accurate information that includes the benefits and

1 This document extends well beyond situations in which the patient is at the end-of-life.

risks as well as alternative methods to provide for basic needs of life during end-of -life care, and represents patient preferences. If a patient chooses to receive hydration and nutrition~~food~~, even if that intake may cause harm (e.g., oral feedings in people who are at risk of aspirating), the nurse is responsible for minimizing risk (i.e., using positional changes and slow, assisted feedings). This is consistent with the ANA's values and goals of respect for autonomy, relief of suffering, and expert care at the end of life (ANA, 2015; ANA, 2016). When a client expresses a desire to voluntarily stop eating and drinking (VSED) with the intention of hastening death, the nurse has an obligation, based on his/her advocate role, to explore this decision along with the patient~~,~~ and determine whether the patient's decision is the result of neglectful care. It is imperative that clients expressing a desire to hasten death be screened for emotional and spiritual suffering, mental health conditions, adequate symptom management, and socioeconomic stressors. Patients who decide to hasten their death due to the effects of poor nursing or medical care have been treated unjustly, or even criminally. Decisions compelled by neglect or abuse are not free choices.

If it is determined that the patient has freely consented to withhold nutrition or hydration that can be assimilated, without causing disproportionately harmful side effects, or even benefit them, the nurse should not be compelled to cooperate in this passive form of suicide, (i.e., providing sedation to diminish the sense of deprivation). The nurse must, while expressing compassion and providing all basic care critical to the patient's wellbeing, continue to educate the patient and encourage physiologically beneficial nutrition and hydration.

It must be understood that the decision to ~~voluntarily stop eating and drinking (~~VSED~~)~~ with the intention of hastening death can be made only by the patient, not by surrogates, or by health care providers~~.~~ A patient's truly informed, non-coerced, and non-changing decision regarding VSED

remains binding, even if the patient subsequently loses capacity.

History/Previous Position Statements

In 1992, the ANA Board of Directors approved the position statement, "Forgoing Nutrition and Hydration". The statement was developed by members of the Task Force on the Nurses' Role in End of Life Decisions. The position statement was revised in 1995 and last revised by the Congress on Nursing Practice and Economics, and approved by the ANA Board of Directors, on March 11, 2011. Related documents include the *Code of Ethics for Nurses with Interpretive Statements* (2015) and the ANA End of Life Position Statement (ANA, 2016).

Supportive material

The fundamental principle that underlies all nursing practice is respect for the inherent dignity of all individuals. That respect is operationalized through the principles of respect for autonomy and self-determination, and manifested in dimensions of culture, values, religious or spiritual beliefs, lifestyle, social support system, sexual orientation or gender expression, and primary language. "Patients have the moral and legal right to determine what will be done with and to their own person" (ANA, 2015, p. 2). They have the right to accurate, complete, and understandable information, and to be supported as they weigh~~t~~ the benefits, burdens, and options for their treatments, including the choice to refuse a particular treatment through the informed consent process (ANA, 2015). When the patient lacks decisional capacity, the surrogate makes decisions as the patient would, based on the patient's previously expressed wishes and known values. Nurses and other caregivers should assist patients and their surrogates with decisions about accepting or forgoing nutrition and hydration through promotion of advance care planning conversations (ANA, 2015). The patient's or surrogate's right to forgo nutrition and hydration is well established (Nelson, 1986; Cruzan v. Director, Missouri Department of

Health, 1990; Schiavo v. Schindler, 2001).2 Advance directives allow adults with decisional capacity to appoint surrogate decision makers who can accept, modify, or refuse treatments on the patient's behalf, should the patient lose capacity, or if the patient chooses not to participate in decision making. However, any decision that involves directly intending to hasten death by withholding nutrition or hydration by any route never should be made by a surrogate. Such a situation exists when clinically appropriate nutrition or hydration is withheld.

Formatted: Not Highlight

Food and fluids are universally understood as necessary to sustain life and promote healing. A key component of nursing care is the assessment and management of the nutritional needs of patients throughout the lifespan. Caring is a characteristic central to the nursing profession. The rich symbolism of feeding is intimately linked to caring, compassion, nurturing, and commitment. Social encounters, developmental memories and human interactions often center on events that involve food and drink. The acts of feeding and providing fluids are closely tied to humankind's basic beliefs regarding care (van de Vathorst, 2014). At end of life, a person's need for food and fluids, however administered, is typically decreased. As patients become sicker, and approach the end of life, physiological indications change, including routes and amounts of nutrition and hydration (van de Vathorst, 2014). Patients and their surrogates often look to nurses to explain diagnosis, prognosis, and treatment options, including those related to nutrition. Options for nutrition and hydration should first consider what is physiologically possible. Based on options developed with an accurate understanding of the patient's disease processes, the patient's (or surrogate's) values can be elicited. Decisions to receive ~~provide~~ food

2 Please note that these cases stand in contradiction to the earlier statement that VSED decisions to hasten death must be made only by patients and not their surrogates. These were both cases where there was no Advanced Directive and surrogates made decisions to withhold hydration and nutrition with the intention of hastening death. Therefore, these are not truly supportive of the position statement. Furthermore, neither of these women were terminally ill.

and fluid at the end of life reflect personal desires, cultural and religious beliefs, lifestyle, and support systems. Beliefs and attitudes about nutrition and hydration at the end of life may be rooted in religion, ethnicity and culture. A basic understanding of patients' cultural, ethnic, and religious or spiritual beliefs and values may help support patients and families.

To allow for a fully informed decision that respects personal and cultural values, patients and surrogates should be advised that low nutrient levels can lead to mental confusion and can impact the dying experience since malnourished patients who are experiencing mental confusion may not be able to behave in a manner congruent with their personality, recognize loved ones, or express their thoughts or feelings coherently at this very vulnerable and intimate time.

Chaplains and other resources on cultural values should be accessed, enabling the nurse to address patients' spiritual needs (Druml et al., 2016).

In some cases, the continued provision of calories and fluid can no longer benefit a patient, and in fact, can cause harm. For example, patients nearing the end of life have decreased caloric needs. Continuing fluid and calories based on prior intake can lead to edema, heart failure, and pulmonary congestion (Groher & Groher, 2012). While the use of nasogastric (NG) or percutaneously inserted gastrostomy (PEG) tubes were previously considered the norm for people who lost the ability to swallow, and who were at risk for aspiration, it is now known that the provision of PEG tubes and other artificial nutrition and hydration is contraindicated in patients with dementia and other diseases at the end of life (Groher & Groher, 2012; Ribera-Casado, 2015). 3

3 This statement is misleading. The Grober & Grober article does not state or suggest that the provision of PEG tubes and other artificial nutrition and hydration is contraindicated in patients with dementia or other diseases at the end of life. The Grober and Grober article states that PEG tubes have not been shown to decrease the incidence of aspiration pneumonia or to prolong survival (Grober& Grober, p.151).

The article by Ribera-Casado also does not state a contraindication. It quotes the American Geriatrics Society's statement that tube feedings are "not recommended" in **terminal adults with dementia** (this is the terminology that

The Academy of Nutrition and Dietetics (2013) has adopted the position that individuals have the right to request, modify, or refuse nutrition and hydration as medical treatment (p.1). Their position asserts that when nutrition and hydration are no longer likely to benefit the patient, or when the burdens outweigh the benefits received, it is ethically appropriate to withhold or withdraw nutrition and hydration.4 Certain conditions are recognized as appropriate for cessation of artificial nutrition and hydration, as long as the intent is not to hasten death, and the physiological side effects of their administration outweigh the benefits. These conditions include severe neurological conditions, proximate death from any pathology, and irreversible total intestinal failure -(Academy of Nutrition and Dietetics, 2013). 5

Dementia, recognized as a terminal illness, is also associated with anorexia and cachexia. Individuals with end-stagte dementia lose interest in food, and often become too confused or

---

should be used in the ANA document if the Ribera-Casado article is going to be quoted).

Not recommended and contraindicated are two very different propositions. In addition, the non-recommendation is due to behavioral concerns, such as agitation and the possibility of a client with dementia pulling out the PEG tube- it is not related to the dying process. In fact, the statement by the American Geriatrics Society quoted by Ribera-Casado recommends that hand feeding continue and states "Careful hand feeding should be offered... hand feeding has been shown to be as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status, and comfort" (p.89). Therefore, there is actually a recommendation to feed the client using hand feeding.

We strongly recommend that the ANA check its references and sources and take more care in faithfully representing literature findings.

4 Please clarify. The article does not actually assert this per se. It only states that weighing the benefits/burdens of artificial nutrition is part of what clients and families must do when engaging in a decision making process about the use of artificial nutrition. Rather than making a statement on whether nutrition or hydration are appropriate under certain conditions, the article is patient-centered and outlines a framework for decision-making that includes burden/benefit considerations. The article does state that when patients are in persistent vegetative states (PVS), the burden/benefits of ***artificial nutrition*** must be considered (p.6). The article's wording is as follows[emphasis added]: "The potential benefits versus burdens of **enteral tube feeding or parenteral feeding** should be weighed on the basis of specific facts concerning the individual's medical and mental status, as well as on the facility's options and limitations"(p.4).

5 This also requires clarification. The statement being referenced actually states: "Three conditions are commonly recognized as justification for removal of nutrition and hydration: neurological devastation, proximate death from any pathology, and irreversible total intestinal failure…The intent is not to hasten death, but to emphasize quality of life." (Academy of Nutrition and Dietetics, 2013, p.6). Additionally, this quote was taken from the section of their statement that deals with the pediatric population. Inserting immediately before statements on patients with Dementia is confusing and requires clarification. Furthermore, not all of these conditions place persons at the end-of-life, which this document purports to address.

refuse to eat. Some hold that t~~T~~here is no evidence that enteral tube feeding provides any benefit for individuals with dementia in terms of survival, mortality, quality of life, physical function, skin integrity or nutritional parameters (Academy of Nutrition and Dietetics, 2013). Feeding tubes have been associated with poor outcomes for patients residing in nursing facilities (Academy of Nutrition and Dietetics, 2013). For these reasons the Academy of Nutrition and Dietetics recommends the following for clients with end-stage dementia: "Rather than enteral tube feeding, the preferred intervention for providing nutrition for individuals with advanced dementia is usually total assistance with oral feedings" (p.6). Furthermore, each case requires an individual assessment of whether these methods of oral feedings are more beneficial to the patient compared to the physiological burdens to the patient caused by the methods used to provide the mechanically assisted nutrition and hydration.

Individuals at the end of life might ~~do~~ not experience hunger or thirst; therefore, a decline in intake with associated weight loss is a natural progression of end-stage disease (Academy of Nutrition and Dietetics, 2013).[6] The absence of food and fluid results in ketosis, and releases opioids in the brain, which may produce a sense of euphoria (Academy of Nutrition and Dietetics, 2013).

Voluntary Stopping Eating and Drinking

People choose to consider forgoing nutrition and hydration for a number of reasons. The decision to voluntarily and deliberately stop eating and drinking with the primary intention to hasten death is known as VSED (Ivanović, Büche, & Fringer, 2014; Lachman, 2015). Nurses may encounter individuals who choose to forgo food and fluid. It is beyond the scope of this position statement to address all situations of refusal to eat and drink; for example, hunger

6 The reference states clients "might" not experience hunger or thirst (American Academy of Nutrition and Dietetics, 2013, p.9).

strikes. There is some consensus (though not universal agreement) that VSED can be an ethical and legal decision (Lachman, 2015; Pope & West, 2014). However, nurses must remain aware that intentionally causing a patient's death is, not only an illegal and criminal act, but also an act that stands in full contradiction of what it means to be a nurse.

For VSED to be an informed decision, the patient must not be encumbered by depression or other factors that impede decision making. When a client expresses a desire to voluntarily stop eating and drinking (VSED) with the intention of hastening death, the nurse has an obligation, based on his/her advocate role, to explore this decision along with the patient and determine whether the patient's decision is the result of neglectful care. It is imperative that clients expressing a desire to hasten death be screened for emotional and spiritual suffering, mental health conditions, adequate symptom management, and socioeconomic stressors. Patients who decide to hasten their death due to the effects of poor nursing or medical care have been treated unjustly, or even criminally. Decisions compelled by neglect or abuse are not free choices. If it is determined that the patient has freely consented to withhold nutrition or hydration that can be assimilated without causing disproportionately harmful side effects, or even benefit them, the nurse should not be compelled to cooperate in this passive form of suicide, (i.e., providing sedation to diminish the sense of deprivation). The nurse must, while expressing compassion and providing all basic care critical to the patient's wellbeing, continue to educate the patient and encourage physiologically beneficial nutrition and hydration.

-The decision to stop eating and drinking with the intention of hastening death can never be made by anyone but ~~must be made by~~ the patient. This decision can never be made by a surrogate or health care provider; the "voluntary" dimension of this term must be the patient's decision. A patient's decision regarding VSED is binding, even if the patient subsequently loses capacity.

Some people who choose VSED may not be close to death. Psychological, spiritual, or existential suffering, as well as physical suffering can lead to patient requests for hastened death. There is an extensive knowledge base to help manage the burden of most physical symptoms. Symptom control is imperative. Conversely, patients who are at the end of life likely have reasons for stopping nutrition and hydration, such as physiologic causes that lead to loss of appetite and/or the inability to eat. For many patients, maintaining control is also important in their dying. Terminally ill patients who are no longer able to eat do not suffer,[7] as long as adequate palliation of symptoms such as dry mouth is provided (Clarke et al., 2013). ~~VSED at the end of life is used to hasten death, and is a reflection of respect for autonomy, and the patient's desire for control.~~ [8]

Summary

When a patient at the end of life or the patient's surrogate has made the decision to forgo nutrition and/or hydration, the nurse continues to ensure the provision of high quality care, minimizing discomfort and promoting dignity. The nurse has an obligation to determine if the reason to forgo nutrition and hydration, regardless of the route of administration, is to hasten death, and be alert for any indication that the patient has had a change of mind. Furthermore, if the motivation is to hasten death, or to deny clinically appropriate nutrition or hydration, such a decision can only be made by the patient. Meticulous oral care should be provided in addition to comfort care, human touch, and palliative care.

Nurses are responsible for understanding the physiologic factors that frame clinical options.

Formatted: Not Highlight

7 This is just not true. Your own (if cited accurately) citations state: "might" not experience hunger or thirst (American Academy of Nutrition and Dietetics, 2013, p.9).

8 This statement is suggestive of a VSED as a "standard of care", which it is not. It is a patient decision that nurses are not and should not be compelled to validate if it conflicts with their own moral code. Additionally, to state that VSED is always a reflection of autonomy imposes a western, individualistic view of autonomy on the broader population- many of which embrace autonomy as a relational concept. Autonomy is not limitless and health care providers are not on-demand vending machines.

Nurses should also have the knowledge and skills to address changing nutritional needs in the face of terminal illness.

When the client decides to voluntarily stop eating and drinking in order to hasten death, nurses have an obligation to explore whether the decision is due to the effects of neglectful care, to advocate for just care, and to report criminal activity. Nurses who have an informed moral objection to either the initiation or withdrawal of nutrition or hydration, should communicate their objections whenever possible to provide safe alternative nursing care for patients, and avoid concerns of patient abandonment. People are drawn to nursing from a desire to provide care. That desire is deeply human since it expresses solidarity with others in their suffering. By giving care, nurses thus display the dignity they possess as human beings. Mandating cooperation by nurses with actions directly intended to hasten death forces nurses to act against such basic beliefs and the very human desire to give care. It thus violates the dignity of nurses conscientiously opposed to VSED, and the withholding of proportionately beneficial assisted nutrition and hydration, and thereby contravenes the fundamental principle that underlies all nursing practice: respect for the inherent dignity of all individuals.

(ANA, 2015).

Recommendations:

- **Nurses must be knowledgeable about the complexity of this issue, discerning if the decision to forgo nutrition and hydration are truly based on the patient's own preference, uncoerced by significant other's biased interest such as financial advantage Kolkaba(2002**
- Nurses recognize those situations when nutrition and hydration can no longer benefit a patient, ~~and adhere to clinical standards that include providing nutrition and hydration only to patients for whom it is indicated.~~ 9
- Nurses will respect the decisions of ~~P~~patients with decision making capacity, or their surrogates, who are relying on the patients' preference, ~~or~~ have knowledge of the person's values and beliefs, and are acting in the patient's best interests, who accept,

Formatted: Not Highlight

9 This is not patient-centered. Additionally, this document has not demonstrated a standard of care along these lines.

modify, or refuse clinically appropriate nutrition and hydration at the end of life. ~~will be supported in decision making about accepting or refusing clinically appropriate nutrition and hydration at the end of life.~~ However, the surrogate may not direct the withholding of clinically appropriate nutrition or hydration unless the patient's advanced directive explicitly indicates consent for such withholding.

- Nurses will have adequate and accurate information to understand patients' cultural, ethnic, and religious beliefs and values regarding nutrition and hydration at the end of life. Patients' views and beliefs should be respected, but nurses are not to facilitate actions or omissions directed toward hastening death.
- Nurses will provide ~~support patients and surrogates in the decision making process by providing~~ accurate, precise, and understandable information about risks, benefits, and alternatives.
- Decisions about accepting, modifying, or forgoing nutrition and hydration will be acknowledged ~~honored~~, including those decisions about artificially delivered nutrition as well as VSED.
- ~~People with decision making capacity have the right to stop eating and drinking as a means to hasten death.~~ 10

Supersedes

ANA Position Statement ***Forgoing Nutrition and Hydration*** March 11, 2012

Formatted: Not Highlight

10 This is not a nursing recommendation. It may be a legal statement of fact, but not a nursing recommendation. Nowhere does the draft recognize the conscience rights of nurses who refuse to collaborate with VSED. In contrast, even legislation legalizing assisted suicide protects conscience rights. For example, Oregon, the first state to authorize such practice, ensures that "[n]o health care provider shall be under any duty, whether by contract, by statute or by any other legal requirement to participate in the provision to a qualified patient of medication to end his or her life" and prohibits any "professional organization or association, or health care provider, … [from] subject[ing] a person to censure, discipline, suspension, loss of license, loss of privileges, loss of membership or other penalty for … refusing to participate[.]" Oregon further protects the conscience rights of institutional providers by authorizing them to prohibit participation in assisted suicide on their premises.

References

Academy of Nutrition and Dietetics (2013). Practice paper of the Academy of Nutrition and Dietetics: Ethical and legal Issues in feeding and hydration. Retrieved from *http://www.eatrightpro.org/resource/practice/position-and-practice-papers/practice-papers/practice-paper-ethical-and-legal-issues-in-feeding-and-hydration.*

American Nurses Association. (2015). *Code of ethics for nurses with interpretive statements*. Silver Spring, MD: Nursebooks.org.

American Nurses Association. (2016). *Registered Nurses' Role and Responsibilities in Providing Expert Care and Counseling at the End of Life*. Silver Spring, MD: Author.

Clarke, G., Harrison, K., Holland, A., Kuhn, I., & Barclay, S. (2013). How are treatment decisions made about artificial nutrition for individuals at risk of lacking capacity? A systematic literature review. *PLoS One*, *8*(4), e61475. doi: 10.1371/journal.pone.0061475

Cruzan v. Director, Missouri Department of Health 58 U.S.L.W. 4916 (25 June 1990).

Druml, C., Ballmer, P. E., Druml, W., Oehmichen, F., Shenkin, A., Singer, P., ... & Bischoff, S. C. (2016). ESPEN guideline on ethical aspects of artificial nutrition and hydration. *Clinical Nutrition*, *35*(3), 545-556. Retrieved from http://dx.doi.org/10.1016/j.clnu.2016.02.006

Groher, M. E., & Groher, T. P. (2012). When safe oral feeding is threatened: End-of-life options and decisions. *Topics in Language Disorders*, *32*(2), 149-167. doi: 10.1097/TLD.0b013e3182543547

Heuberger, R. A. (2010). Artificial nutrition and hydration at the end of life. *Journal of Nutrition for the Elderly*, *29*(4), 347-385. doi: 10.1080/01639366.2010.521020.

Hospice and Palliative Nurses Association (2004). Artificial nutrition and hydration in end-of-life care: HPNA position paper. Home Healthcare Nurse, 22:5, 341-345.

Ivanović, N., Büche, D., & Fringer, A. (2014). Voluntary stopping of eating and drinking at the end of life–a "systematic search and review" giving insight into an option of hastening death in capacitated adults at the end of life. *BMC Palliative Care*, *13*(1), 1. doi:10.1186/1472-684X-13-1

Kitzinger, C., & Kitzinger, J. (2015). Withdrawing artificial nutrition and hydration from minimally conscious and vegetative patients: family perspectives. *Journal of Medical Ethics*, *41*(2), 157-160. doi: 10.1136/medethics-2013-101799

Kolkaba K. (2002). *Comfort theory and practice. A vision for holistic health care and research.* New York; Springer.

Lachman, V. D. (2015). Voluntary stopping of eating and drinking: an ethical alternative to physician-assisted suicide. *Medsurg Nursing*, *24*(1), 56-60.

Nelson, L. J., "The Law, Professional Responsibility and Decisions to Forgo Treatment," Quality Review Bulletin, Joint Commission on Accreditation of Hospitals, January 1986. Omnibus Budget Reconciliation Act of 1990, Public Law 101-508, Sec. 4207 and 4751.

Pope, T. M., & West, A. (2014). Legal briefing: Voluntarily stopping eating and drinking. *Journal of Clinical Ethics*, *25*, 68.

Ribera-Casado, J. M. (2015). Feeding and hydration in terminal stage patients. *European Geriatric Medicine*, *6*(1), 87-90. doi:10.1016/j.eurger.2014.11.009

Schiavo v. Schindler, No.90-2908GD-003. (Fla. 2000).

Schwartz, D.B., Posthauer, M.E., & Maillet, J.O. (2013). Practice paper of the Academy of Nutrition and Dietetics abstract: Ethical and legal issues of feeding and hydration. *Journal of the Academy of Nutrition & Dietetics, 113,* 981. doi:10.1016/j.jand.2013.05.006

van de Vathorst, S. (2014). Artificial nutrition at the end of life: Ethical issues. *Best Practice & Research Clinical Gastroenterology*, *28*(2), 247-253. doi: 10.1016/j.bpg.2014.02.005