



National Hospice & Palliative Care Organization

COMMENTARY AND POSITION STATEMENT ON ARTIFICIAL NUTRITION AND HYDRATION

Introduction:

As the world's leading hospice and palliative care advocacy organization, the National Hospice and Palliative Care Organization (NHPCO) is dedicated to advancing the philosophy and practice of hospice and palliative care so that the needs of all individuals and their loved ones can be met at a time in their lives when comfort, compassion and dignity matter most. In its vision, NHPCO promotes a world where individuals and families facing serious illness, death, and grief will experience the best that humankind can offer.

Background:

The goals of palliative care and of hospice care include providing people facing a serious or terminal illness or injury with high quality, compassionate care that is expressly tailored to the patient's needs and wishes in the context of the patient's current state of illness or injury. Within the bounds of this goal, patients and their families have considerable latitude in the choices that they make regarding the patient's care. When the decisions include artificial nutrition and hydration (ANH), usually one of three options is being considered: whether to start the therapy, whether to continue the therapy, or whether to discontinue the therapy.

During the course of a serious illness or as the patient is dying, the patient may become unable to eat or drink. In many cases, the administration of nutrition and hydration does not contribute to the goals of care for the patient, and may, in fact, create a physiologic burden. Patients always have the option to forgo food or fluid without medical intervention, however, in many instances healthcare providers become involved in the decision making regarding the use of nutrition and hydration delivered through medical intervention. These decisions commonly include dimensions related to the appropriate initiation, continuation, or discontinuation of ANH.

Several professional organizations have issued guidelines and position statements that illuminate the ethical issues that underlie this decision making process.¹⁻³ These organizations have made it clear that decisions about the initiation, continuation, or discontinuation of ANH should be made in the same way that other health care decisions are made: by evaluating the risks and potential benefits of available alternatives in light of pathophysiologic parameters, the goals of treatment, and the patient's preferences. This statement offers ethical guidance for clinicians, patients, and families who are addressing the question about the optimal utilization of ANH with seriously or terminally ill and their families.

Analysis

What burdens and potential benefits should clinicians consider in making decisions about ANH?

- The appropriateness of any medical therapy must first consider medical indications, and then consideration of benefits and burdens, goals of care, and then patient and family values and preferences.⁴
- ANH may or may not prolong life, depending on medical circumstances. There are not only numerous medical indications for ANH, but also situations in which prolonged ANH can sustain a high quality of life. For example, in the short term, ANH is routinely used post-surgically when the bowel must be rested and nutrition must be maintained. In the long term, patients with short gut syndrome have been maintained on ANH for years. ANH may also impart benefit in cases such as when swallowing is impaired temporarily (e.g., with certain strokes), or instances in which swallowing is impaired (as with a locally advanced esophageal tumor) but the patient's condition is otherwise good. The benefit of ANH changes for those who are dying. Instead of supporting a high quality of life, ANH may prolong the dying process and impose significant burdens on the dying patient. In many conditions, ANH does not prolong life.⁵⁻⁷
- ANH requires the placement of a temporary or permanent enteral feeding tube (e.g., nasogastric, orogastric, percutaneous endoscopic gastrostomy, other surgically inserted gastrostomy tube (G Tube), jejunostomy tube (J tube), radiographically inserted gastrostomy (RIG)), or the use of intravenous access. These interventions are associated with risks (e.g. bleeding, displacement, infection) and burdens (discomfort, need for repositioning or replacement).^{6, 8-11} Patients may refuse these interventions if they are inconsistent with their conception of a good quality of life. Medical teams should choose not to offer ANH if it cannot provide benefit for the patient.
- ANH administered by a feeding tube does not prevent aspiration pneumonia, and probably increases the risk compared to patients who do not receive anything by mouth.^{9, 10}
- ANH may also increase discomfort due to volume overload (e.g. pulmonary edema and dyspnea) or gastrointestinal disturbance (e.g. nausea, diarrhea).
- ANH is unlikely to reduce the discomfort that may be associated with hunger or thirst.¹²

- A decreased appetite and minimal caloric demands are a part of many advanced diseases, and are a part of the dying process.¹³ The malnutrition of terminal illness is different from a lack of nutrients.¹⁰ A dry mouth and lips are different symptoms than thirst, and should be treated differently. Further, if a patient is hungry or thirsty, and is able, the patient should be allowed to eat and drink.

How should clinicians and other professionals consider patients' preferences?

- All too often, the provision of ANH is not seen as a medical intervention, but merely as the provision of food and water. This leads to an all too casual and automatic recommendation in favor of its provision. By viewing ANH as a medical intervention, its indications, benefits, and burdens are more readily considered. In the past, the medical community was unsure of the potential benefit of ANH for those with end stage conditions such as dementia and other advanced diseases. We now know that ANH does not add to the comfort of those who are dying, and in fact, may not substantially prolong their lives.
- In general, patients (or their surrogates) have the right to refuse treatment if they find its balance of risks, burdens, and potential benefits to be unacceptable.¹³
- Similarly, there is widespread agreement among ethicists,¹² the legal and judicial communities,^{15,16} and health care providers that patients (or their surrogates) have a right to choose or refuse ANH.
- Many patients, families, and other clinicians believe that ANH differs from other medical treatments, that ANH are unique, and cannot be discontinued. Some describe ANH as “ordinary” (vs. “extraordinary”) or proportionate (as opposed do disproportionate) interventions that cannot be withheld or withdrawn. In large part, these beliefs may arise from religious and cultural norms to which patients and families adhere. Therefore, nutrition in any form may take on significant symbolic value for patients and their families, leading to the perception that withholding or withdrawing ANH is equivalent to “starving” a patient.
- In general, there is no ethical or legal basis for a distinction between ordinary or proportionate and extraordinary or disproportionate¹⁷(pp.123-128). Clinicians should be prepared to explore the moral or religious beliefs that underlie patient and family preferences. When a patient’s or family member’s adherence to this distinction is based on cultural beliefs or religious teaching, consultation with other members of that ethnic/cultural group or clergy may be helpful.
- Clinicians are not bound to accede to demands for treatments that cannot benefit the patient. Family demands for ANH often arise from misunderstandings in the context of a desire to do the right thing. Education, rather than the provision of ANH is the appropriate intervention in these cases.
- In situations in which the benefits and burdens are not clear, the use of a *time limited* clinical trial to determine whether benefit will accrue is appropriate.

Who should make decisions about ANH?

- These decisions should ideally be made by a patient with decision making capacity. Providers should be prepared to perform an assessment of decision making capacity to ensure that the patient: 1) understands the medical situation and choices; 2) appreciates that the choice is relevant to him/her; 3) can weigh the risks and potential benefits of the

intervention; and 4) can express a choice that is consistent with his/her assessment of the relevant risks and potential benefits.^{18 - 19}

- If the patient lacks decision-making capacity, choices may be made by a surrogate decision-maker who knows the patient's preferences. Providers should obtain enough evidence of the patient's wishes to be confident that the medical plan would have been consistent with the patient's wishes. Providers should also be aware that some state legislation requires a higher level of certainty ("clear and convincing evidence") that a patient would not have wanted artificial nutrition and hydration. Regardless of the evidence standard being used, the decision should be consistent with the best available evidence about:
 - The medical indications
 - The goals of care for this patient
 - The patient's preferences regarding life-sustaining treatment
 - The patient's preferences regarding artificial nutrition and hydration
 - Religious and spiritual beliefs and/or past experiences that might bear on the decision
- If the patient lacks decision-making capacity and no surrogate decision-maker has any knowledge of the patient's preferences, artificial nutrition and hydration may be withheld or withdrawn if doing so would be in the patient's best interests. In these cases, an ethics consultation is recommended.

Is it appropriate for the patient's clinician to make recommendations?

- Decisions about ANH should be made in a carefully reasoned process by patients or their surrogates, based on information from the clinical team.^{20, 21} Patients or their surrogates frequently look to their clinical care team for guidance. Providers should be able to discuss the benefits and burdens of the intervention as a context for the application of the patient's preferences.

Because ANH can be a particularly burdensome intervention, there are often cases when it should either not be initiated, or it should be discontinued. These may be particularly difficult recommendations for clinicians, as well as for the patient and family. Clinicians' recommendations for withholding or withdrawing this treatment, as with any other, may lead to challenging encounters. Under these circumstances, it is important that clinicians maintain their relationship with the patient and family, and continue to support the patient's and family's goals and values as much as possible. At the same time, treatments for which the burdens outweigh the benefits should not be continued or started. Institutional policies supporting processes for addressing family disagreements in general, and the appropriate use of ANH in particular can be helpful in addressing these situations.

Is there an ethical difference between withholding (not starting) ANH and withdrawing ANH once it has been initiated?

- There is no legitimate ethical distinction between withholding and withdrawing artificial nutrition and hydration.^{17(pp.120-123)} In general, if it is acceptable to withhold a therapy, it is also acceptable and indeed responsible to withdraw it.
- If ANH are discontinued, continued excellent medical care is still indicated. This may take the form of consultation with the palliative care service.

Foregoing artificial nutrition and hydration in children

The same principles regarding withholding or withdrawing life prolonging therapies that apply to adults apply to children. “The provision of medically provided fluids and nutrition is morally optional if it does not provide a net benefit to the child² (p. 815). Terminally ill children almost always know that they are dying²² and are able to participate in decision making.²³ Because infants and some children cannot make informed decisions about their care, parents are the presumed decision makers for children. For children who are aware, ANH may provide a benefit to the child. As with adults, the physiologic potential for ANH to benefit the child must first be considered. Only after medical indications for ANH are identified should treatment options be constructed. If ANH cannot benefit the child, for example, for a child with anencephaly, a child who never possessed consciousness, or a child who will not regain consciousness, ANH should not be offered. If ANH has been provided and it is realized that a child will not regain awareness, or otherwise will not benefit, ANH should be discontinued. When a child is dying, ANH may not contribute to the child’s comfort and may impose significant burdens, including nausea, vomiting, diarrhea, increased secretions, dyspnea, and other symptoms.²

Parents who are involved in these situations may need particular support. Because myths about the use of ANH are common, it may be helpful to provide recommendations for support from people with specific expertise in the integrations of ethics into clinical decision making. This decision making is often a prolonged process. Ample time to integrate information that may ultimately be related to the death of a child *must* be allowed. Bereavement support and an ethics consultation may help.

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Statement and Commentary Conclusion

With its mission to lead and mobilize social change for improved care for patients with serious illness or who are at the end of life, NHPCO seeks to sustain the individual’s and family members’ sense of respect for autonomy, individuality, self-worth, and security, and to care for the whole person, addressing physical, emotional, psychological, spiritual and social concerns through an interdisciplinary team approach.

- Decisions about artificial nutrition and hydration should be made in the same way as decisions about other treatments, by considering the clinical facts of the case, and then patient’s preferences and the relevant risks and potential benefits.
- It is always acceptable to withhold or withdraw artificial nutrition and hydration when a patient with decisional capacity refuses, or when adequate evidence exists that a patient without decision making capacity would have found the balance of risks and potential benefits to be unacceptable.
- It is acceptable and right to withhold or withdraw artificial nutrition and hydration when doing so is in the patient’s best interests.

- Providers should work aggressively to minimize predictable suffering and to maintain provider integrity.
- Consultation with palliative care providers whose expertise includes end of life care can facilitate optimal decision making and other patient and family care.

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**Developed by:
National Hospice and Palliative Care Ethics Committee**

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