



## HPNA Position Statement Artificial Nutrition and Hydration in Advanced Illness

### Background

**The following position statement is based on evidence that reflects patients with advanced illness and may not be applicable in all palliative circumstances.**

Patients with advanced illness often experience a natural decline in appetite, loss of interest in eating and drinking, and weight loss. Some patients may experience dysphagia, which also decreases oral intake. At some point in the illness trajectory, most patients will either be unable to take food and fluids by mouth or will refuse food.<sup>1, 2</sup> These changes can cause distress, especially for families and other caregivers, and raise questions about artificial nutrition and hydration (ANH).<sup>2</sup> Many patients, families, and other caregivers fear that undernourished patients may experience hunger. They may also believe that dehydration results in troublesome symptoms such as thirst, dry mouth, headache, delirium, nausea, vomiting, and abdominal cramps.<sup>3</sup>

Artificial nutrition and hydration (ANH) interventions were originally developed to provide short-term support for patients who were acutely ill and are often used to provide a bridge to recovery, or to meet therapeutic goals of prolonging life. There are few well designed studies that have examined the effectiveness of ANH in meeting these goals.<sup>4</sup> One of the most important aims of hospice and palliative care is to minimize suffering and discomfort. When ANH is used in patients with advanced illness in the terminal phase, the evidence suggests that these measures are seldom effective in preventing suffering. ANH is a medical intervention that should be evaluated for each individual, utilizing evidenced-based practices reflecting the benefits and burdens, the clinical circumstances, and the overall goals of care.

There are multiple potential burdens of ANH for patients with advanced illness. Studies have shown that tube feeding does not appear to prolong life and complications from tube placement may increase mortality in certain populations.<sup>5</sup> Furthermore, artificially-delivered nutrition does not protect against aspiration and in some patient populations may actually increase the risk of aspiration and its complications. Tube feedings are associated with increased

infection, fluid overload, and skin excoriation around the tube.<sup>2</sup> Since many tube fed patients are not offered food, even if they are able to eat, they may be deprived of human contact and the pleasure of eating. Other discomforts associated with tube feedings include exacerbation of nausea, vomiting, and diarrhea, as well as throat and nose pain and altered tissue integrity from nasogastric tubes.<sup>6</sup> Artificial nutrition and hydration in patients with advanced illness may lead to life threatening fluid overload complications related to edema, increased secretions, ascites, and pleural effusions.<sup>4,7</sup> Research has shown that artificial nutrition and nutritional supplements do not enhance frail elders' strength and physical function. Finally, therapies such as ANH that require the use of tubes increase the likelihood that patients will be restrained. Physical restraints are distressing and often increase patient agitation and skin breakdown.

Studies show that most actively dying patients do not experience hunger even if they have inadequate caloric intake. Many patients may experience thirst or dry mouth, but this symptom is not only associated with fluid status; therefore parenteral fluids are unlikely to alleviate thirst.<sup>8</sup> Good oral care, ice chips, or moistening the mouth often will provide more relief than artificial nutrition or hydration.

Artificial nutrition and hydration can sometimes offer symptomatic benefit to patients with advanced illness in the setting of reversible or acute illness. Some studies suggest that ANH may help with reversing myoclonus and opioid toxicity.<sup>8,9</sup> For patients experiencing temporary symptoms of nausea, vomiting, or diarrhea, a temporary trial of hydration can assist with electrolyte imbalances and symptoms.<sup>3</sup> ANH can also be beneficial in functional patients with mechanical blockage of the mouth, esophagus, stomach, or bowel.<sup>3</sup> If there is uncertainty about whether a patient will benefit from ANH, a time-limited trial may be useful. The caregiving team should support the patient and family in creating goals for treatment, as ANH can be withdrawn if it is not achieving its desired purpose.

For some patients and families, ANH may have symbolic importance beyond the measurable effects on the patients well-being. Such views should be assessed in a culturally sensitive setting with respect to patient and family wishes.<sup>10</sup> It is imperative to involve the interdisciplinary team to assist with goals of therapy in relation to sociocultural, financial, spiritual needs.<sup>10</sup>

When patients are incapable of understanding their prognosis and treatment choices or are unable to express their wishes, advance directives and surrogate decision-makers must be consulted. The right of parents to forego or withdraw ANH for children who are unlikely to benefit from the therapy also needs to be honored.<sup>11</sup> The right of *competent* adults to decide whether or not to accept or refuse specific medical therapies is now well established through legal precedent. Artificial nutrition and hydration is considered medical treatment and thus can be requested or refused.<sup>12,13</sup> This right reflects respect for patient *autonomy*.<sup>12</sup> Competent adults may express their decision about ANH and other therapies through advance directives, which should guide care *proxy decision-making* in the event they no longer have decision-making capacity.

## Position Statement

- Acknowledge the decision to initiate, withhold, or withdraw AHN should be made by the patient and family with accurate and nonjudgmental input from the healthcare team.
- Promote the education of healthcare providers to ensure that they understand the clinical, legal, and ethical issues regarding the use of AHN.
- Support education of patient, family, and other caregivers about the dying process and its effects on nutrition and fluid status.
- Teach caregivers to enhance the patient's comfort by providing frequent oral and skin care, effective and timely symptom management, and psycho-spiritual support. Support caregivers in coping with feelings of helplessness, loss, and fear.
- Recognize that in specific situations, ANH may be clinically beneficial. ANH may also be initiated or continued to honor the beliefs and values of some cultural and religious groups.
- Encourage nurses to collaborate with speech therapists, nutritionists, and other healthcare providers to identify and implement strategies that enable caregivers to provide oral nutrition and fluids safely and effectively, as an alternative to ANH.
- Promote the use of a decision-making process that examines the benefits and burdens of ANH and includes the patient's clinical condition, goals, and values.
- Acknowledge and support the established, legal and moral right of competent patients to refuse unwanted treatment, including ANH.
- Acknowledge and support the family's or other surrogate's role as decision-maker in cases where a patient is unable to make his or her wishes known or is unable to evaluate the benefits and burdens of artificial nutrition or hydration.
- Promote the use of advance directives such as living wills or the legal assignment of durable power of attorney for healthcare to document choices and values that should guide care at the end of life in the event that decision-making capacity is lost.
- Promote early discussions about the goals of care and treatment choices, including the expected benefits and burdens of possible end-of-life interventions including ANH, prior to treatment initiation, refusal, or withdrawal.
- Encourage policies that guide a decision-making process for resolving disagreements about care among patients, families, surrogates, and healthcare team members.
- Support research on the outcomes of ANH in diverse groups of hospice and palliative care patients.

## Definition of Terms

*Artificial Nutrition and Hydration:* Artificial nutrition and hydration is considered receiving nutrition in any form other than the taking in of food and fluid through the mouth (orally). This can be achieved through a nasogastric tube (NG tube), a gastrostomy tube (G tube or PEG tube), an intravenous tube (IV), or through total parenteral nutrition (TPN).<sup>14</sup>

*Autonomy:* A multidimensional ethical concept. It is the right of a capable person to decide his/her own course of action. Self-determination is a legal right.<sup>15,16</sup>

*Clinical Practice Guideline:* "Systematically developed statement designed to assist practitioner and patient make decisions about appropriate healthcare for specific clinical circumstances."<sup>17</sup>

*Decisional Capacity:* Decisional capacity refers to the ability of a person to make decisions. Adults are presumed capable unless declared incompetent by a court of law or judge. Some states require two physicians to determine decisional capacity of a particular person. Decisional capacity is specific to a point in time and a specific decision. A clinical evaluation of capacity centers on a person's ability to 1) take in information; 2) understand the relevant information and apply it to his/her own condition; 3) have insight into the condition and consequences of treatment options; 4) be able to communicate the decision and reasoning for choices.<sup>16,18</sup>

*Dysphagia:* Difficulty in swallowing or the inability to swallow.<sup>19</sup>

*Evidence-based practice:* A practice that is based on research, clinical expertise, and patient preferences that guides decisions about the healthcare of individual patients. Evidence-based nursing practice stresses the use of research findings, quality improvement data (as appropriate), other operational, and evaluation data, the consensus of recognized experts, and affirmed experience to substantiate practice.<sup>17</sup>

*Forgoing life-sustaining treatment:* To do without a medical intervention that would be expected to extend the patient's life. Forgoing includes withholding (non-initiation) and withdrawing (stopping).<sup>20</sup>

*Healthcare Agent or Proxy:* A person appointed by the patient to make healthcare decisions if the patient becomes incapable of making her/his own decisions. The proxy has a responsibility to act in accordance with the known preferences of the patient; if the preferences are not specifically known, the responsibility is to act on similar known preferences of the patient. Decisions made by the agent or proxy carry the same legal weight as if made by the patient.<sup>21</sup>

*Interdisciplinary Team:* A group of healthcare professionals from diverse fields who work in a coordinated fashion toward a common goal for the patient.<sup>22</sup>

*Life-sustaining therapies include but are not limited to:* Cardiopulmonary resuscitation; cardiac support devices (pacemakers, internal cardioverters/defibrillators, intraaortic balloon pumps) and cardiac medications; respiratory support devices (invasive and non-invasive mechanical ventilation, oxygen, and respiratory medications); renal support devices (dialysis in any form) and renal medications; blood products; parenteral and enteral nutrition and hydration; cancer treatments; and surgery.<sup>20</sup>

*Palliative Care:* The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, and helping with decision-making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or the main focus of care.<sup>23</sup>, p. 6

*Physical Restraint:* A nursing intervention from the Nursing Interventions Classification (NIC) defined as application, monitoring, and removal of mechanical restraining devices or manual restraints used to limit physical mobility of a patient.<sup>24</sup>

*Principle of Double Effect:* A bioethical concept that provides moral justification for an action that has two foreseen effects: one good and one bad. The key factor is the intent of the person performing the act. If the intent is good (e.g., relief of pain and suffering) then the act is morally justifiable even if it causes a foreseeable but unintended result (e.g., hastening of death).<sup>15</sup>

*Proxy decision-making:* Allowed if the person lacks capacity to make an informed choice. Written advanced directives, substituted judgment based on subjective knowledge of the person's values, views on quality of life, goals, or the "best interest" of the person whose wishes and values are unknown based on benefits/burden weighing of recommended actions are the basis of such surrogate decisions.<sup>15,16, 25</sup>

*Quality:* "The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."<sup>26</sup>

*Starvation:* "People who suffer from starvation have an appetite and want to eat. With starvation, eating more or taking nutrition reverses the weight loss."<sup>27</sup>, p. 627 Loss of appetite is expected in the final stages of a life-limiting illness.

*Suffering:* An individual and private experience characterized by a state of severe distress induced by loss of intactness of person or threat that the person believes

will result in loss of his/her intactness related to physical pain, unrelieved symptoms, spiritual distress, depression, or multiple losses.<sup>28-30</sup>

*Surrogate Decision-Maker:* Someone authorized to make decisions, usually medical or legal, for another person.<sup>31</sup> The role of the surrogate decision-maker is to make decisions for the patient that he/she thinks the patients would have made for them self-based on knowing the patient's values and previously expressed wishes.<sup>32</sup>

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