Invited Review

The Use of Advance Care Planning to Guide Decisions About Artificial Nutrition and Hydration

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ABSTRACT: Advance care planning is important to ensure that patients, when competent, can influence the kind of medical care they receive if they lose decision-making capacity. Because decisions by surrogates to forgo nutrition support remain controversial, specific inclusion of artificial nutrition and hydration as a part of advance care planning has taken on growing importance. This article reviews the choices about artificial nutrition and hydration that are possible using conventional advance directives such as the living will, the instructional directive, values histories, and combination directives. It summarizes the legal basis for such documents. It also describes the ways that physicians' orders to limit treatment can help implement decisions about the use of artificial nutrition and hydration. Finally, it stresses the importance of clarifying with patients and families the risks and benefits of nutrition support in a variety of common situations such as advanced dementia and metastatic cancer as an essential prerequisite to meaningful advance care planning.

As recently as 30 years ago, paternalism was the norm in American medicine: physicians simply told patients what treatment was best for them.[1] Paternalism is still the norm in many other countries, including much of the first world.[2] But the principle of patient autonomy, the right to participate in decisions about one's own health and well-being, has become widely accepted in American healthcare.[3] At the same time, physicians increasingly recognize that there are often several different approaches possible to the treatment of a given medical problem, each with its own set of risks and benefits. As a result, patients can now expect that they will have real choices to make about their medical care, ranging from a purely palliative approach to a maximally aggressive strategy, along with a variety of intermediate strategies.[4]

Choosing medical care is no mere theoretical exercise for the millions of patients who get sick each year. The elderly in particular are at high risk of developing major medical problems, potentially precipitating hospitalization and leading to sophisticated technologic interventions. Unfortunately, just when patients are asked to make difficult decisions about what kind of treatment they prefer, they may be the least well equipped to make those choices. The oldest people are the most likely to become ill; they have the highest rates of dementia, which impairs their decision-making ability. Although only 5% of people over age 65 have dementia, by age 85, the rate of dementia approaches 50%.[5] Further, older people frequently become confused when they are acutely ill because they are predisposed to developing delirium, even if they are cognitively intact when well.[6] Patients who are completely lucid may also find the decision-making demands placed on them overwhelming when they are in the midst of a medical crisis.[7] Because making choices about medical care is both difficult and expected and because many people simply cannot engage in this process when they are in the throes of illness, whether for emotional or physical reasons, advance care planning is often advocated.

Advance care planning, as it has evolved in the United States over the last several decades, can take a number of different forms. One form is a conversation between a patient who is cognitively intact and his physician about what approach to care he would want if he became sick. The physician is left to translate those wishes into action at the time of an acute illness. A second form of advance care planning is for the patient to complete a formal "advance directive," typically a written document that specifies his wishes for future care. Legislation in each state endorses particular versions of advance directives that are recognized in that state, and federal legislation (the Patient Self-Determination Act of 1990) and judicial precedent ("right to die" cases heard before the US Supreme Court or state high courts) recognize the right of a patient to

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Table 1
Artificial nutrition and hydration (ANH) in advance care planning documents

Instrument	Description	Reference to ANH
Living will	Broad directive	None
Instructional directive	Scenario-based directive	May include use of ANH in specific situations (eg, coma, advanced dementia)
Healthcare proxy	Designation of surrogate decision maker	Right to make decisions about ANH restricted in some states
Values history	Philosophical statement about preferences	None
Combination directive	Mini living will, instructional directive, values history, proxy designation	May include ANH in instructional directive component

ANH, artificial nutrition and hydration.

make decisions about his healthcare. Finally, advance care planning can take the form of a physician order, mandating that a particular approach to care be undertaken, should the relevant circumstances arise.

The earliest advance care planning focused principally on invasive, life-sustaining technology, primarily ventilators and cardiopulmonary resuscitation. As bioethical thinking evolved, physicians and patients increasingly recognized that virtually *all* medical interventions have both burdens and benefits and that, especially as patients near the end of life, their weighting of these burdens and benefits might change. At the same time that medical ethics progressed, new technologies were developed in the area of artificial nutrition and hydration (ANH), specifically parenteral nutrition (PN) and percutaneous endoscopic gastrostomy (PEG) tubes; the latter were first introduced in the early 1980s, and between 1988 and 1995, the number of such tubes placed in hospitalized older individuals grew from 61,000 to 121,000.[8] As a result, these technologies figured prominently in decisions about limiting life-sustaining treatment. Because decisions to limit nutrition and hydration continue to be emotionally highly charged, it would seem to be useful to specifically incorporate preferences about their use into advance care planning. This paper summarizes the existing efforts to do exactly that.

Advance Care Planning Instruments

Living Wills

The earliest approach to specifying preferences of a patient for future care in a written document is Luis Kutner's living will (Table 1), proposed in the 1960s.[9] The original living will was a broad, general statement typically indicating that the patient would not want "heroic" measures undertaken in the event of "imminent death." A slightly more specific version, proposed by the philosopher Sissela Bok, states: "If my death is near and cannot be avoided, and I have lost the ability to interact with others and have no reasonable chance of regaining this ability, or if my suffering is intense and irreversible, I do not want to have my life prolonged."[10] After explaining why she would not want her life prolonged, and the circumstances, Bok then says more specifically what she would not want done:

"I would then ask not to be subjected to surgery or resuscitation. Nor would I then wish to have life support from mechanical ventilators, intensive care services, or other life prolonging procedures, including the administration of antibiotics and blood products. I would wish, rather, to have care which gives comfort and support, which facilitates my interaction with others to the extent this is possible, and which brings peace."

Most living wills are vague, referring often to "heroic" or "life-prolonging" measures. Further, they usually apply only to imminent death, rather than to serious, life-threatening illness, which could include advanced heart disease, metastatic cancer, and Alzheimer's disease.

Newer living wills sometimes include information on just what interventions the person would want, such as ANH. But to the extent that they spell out preferences for medical technology, they are equivalent to another type of advance care planning instrument, the *instructional directive*.

Instructional Directives

Precisely because the original living wills were very imprecise, physicians found them problematic. They typically expressed the general sentiment that the patient would not want all possible interventions instituted in an attempt to prolong life, however unlikely these measures might be to be successful and however burdensome they might be. They often articulated a desire to focus on comfort at the very end of life but left open to interpretation how comfort was to be achieved and just when the "end of life" began. To overcome these limitations, physicians and biomedical ethicists sought to create advance directives that were clear about the circumstances in which they would apply and specific about what technologies would be acceptable to the patient in each of various situations.

The most elaborate and influential of these instructional directives is the medical directive put

forward by Emanuel and Emanuel.[11] Their initial formulation asked patients, when well, to imagine which of 12 possibly medically indicated interventions they would want in each of 4 dire scenarios. The scenarios were irreversible coma, coma with a very small chance of recovery (almost certainly to an extremely impaired state), dementia and cancer, or advanced dementia defined as the inability to recognize family members. In each possible situation, the patient was asked to check off whether he would want attempted cardiopulmonary resuscitation (CPR), ventilator treatment, dialysis, chemotherapy, major surgery, invasive tests, artificial nutrition, intravenous (IV) therapy, antibiotics, blood transfusions, simple tests, or pain medication. The patient, or rather the potential patient, could specify that he would want the intervention, would not want the intervention, would want a limited trial of the intervention, or was uncertain. A subsequent reworking of the medical directive lumps "artificial nutrition" and "IV fluids" into a single category, "artificial nutrition and hydration," and makes several other minor modifications to simplify the list of options.[12]

Other versions of instructional directives are increasingly incorporated into living will documents. These often start with a general philosophical statement and then state which of several treatments the individual would want in each of several possible medical states. The states most commonly referred to are *coma*, *imminent death*, and *persistent vegetative state*. The particular technological interventions that the person is asked to comment on for each state are typically *ventilator support*, *cardiopulmonary resuscitation*, and *artificial nutrition and hydration*. For example, the state of Connecticut's official advance directive form states "I request that if my condition is deemed terminal or if I am determined to be permanently unconscious, I be allowed to die and not be kept alive through life-supporting systems." It then defines "terminal condition" as "an incurable or irreversible medical condition which, without the administration of life support systems will, in the opinion of my attending physician, result in death within a relatively short time." It also defines "permanently unconscious" as "permanent coma or persistent vegetative state, which is an irreversible condition in which I am at no time aware of myself or the environment and show no behavioral response to the environment." The person is then asked to specify whether, in these situations, he would want attempted cardiopulmonary resuscitation, artificial respiration, or ANH.[13]

Unfortunately, despite their seeming precision, instructional directives do not address many of the situations in which patients commonly wish to consider limitations of care. A person with moderately advanced dementia, for example, and pneumonia, might wish to decline ventilator treatment for the pneumonia. Her Alzheimer's disease might give her a life expectancy measured in years, so she is hardly terminally ill. Her pneumonia is potentially reversible and is thus also not an irreversible medical condition. Nonetheless, patients frequently request that if they are ever in such a situation, they would want care focused primarily on their comfort.[14] Similarly, a patient who has had multiple strokes, is dependent in all her activities of daily living, and then develops difficulty swallowing might not want a feeding tube placed. Again, this individual has an irreversible underlying medical condition but is not imminently dying. She might nonetheless regard insertion of a PEG tube as excessively burdensome, given her assessment of her quality of life.

Although ANH are among the specific interventions commonly mentioned in instructional directives, they are not universally listed. Further, some directives view ANH as medical interventions, but others seem to imply they are necessary for comfort. The Illinois living will, for instance, begins by saying "If at any time I should have an incurable and irreversible injury, disease, or illness judged to be a terminal condition . . . and my death is imminent, I direct that . . . procedures which would only prolong the dying process be withheld or withdrawn and that I be permitted to die naturally with only the administration of medication, *sustenance*, or the performance of any medical procedure deemed necessary by my attending physician to provide me with comfort care."[15]

An additional limitation of intervention-specific advance directives is that they do not address the reason a particular intervention is proposed.[16] Conceivably, some interventions are so burdensome that patients would not wish them tried, regardless of the potential benefit. But in most cases, it is only by weighing risks and benefits that patients can decide whether or not to accept a proffered intervention. This issue is particularly germane to considerations of ANH. To the extent that individuals (erroneously) believe that failure to receive tube feeding in the setting of advanced dementia, for example, would be associated with physical discomfort, they might well request such interventions.[17] Simply checking off a box indicating they would or would not want ANH does not provide for any clarification of the basis of such a decision.

Healthcare Proxies

Because instructional directives cannot possibly address all possible situations in which patients may find themselves and in which they might want to limit treatment but cannot speak for themselves, many physicians and ethicists came to the conclusion that it was preferable to simply designate a surrogate decision-maker. Known as a healthcare proxy, healthcare agent, or durable power of attorney for healthcare, such a person is empowered to make decisions on behalf of the patient if he or she is no longer able to do so. All 50 states and the District of Columbia now have some sort of healthcare proxy

legislation, recognizing the authority of each individual, when cognitively intact, to appoint someone to make healthcare decisions in the event of incapacity.

The general expectation is that proxies will make decisions according to "substituted judgment." That is, they will try to determine what the patient would want if he were in fact able to speak for himself and decide accordingly. Regrettably, healthcare proxies often have not had conversations with the person they are representing about their preferences. Although many proxies feel they are nonetheless able to make determinations about the wishes of a patient, others do not believe they have the necessary guidance from the patient to make a substituted judgment. In such cases, the usual recommendation is that proxies make choices using a "best interests" standard, or what most people would want in that situation. In fact, there is growing evidence that patients do not want their proxies to use either substituted judgment or best interests but rather to make a reasonable choice based on their knowledge of the patient and the situation.[18]

In principle, a healthcare surrogate should be able to authorize any medical treatment or limitation of treatment. Patients have the right to make decisions about their health and well-being, and in the absence of the cognitive capacity to do so, their designated representative should be able to speak on their behalf. However, legislation in many states restricts the right of proxies to make certain kinds of decisions or decisions in particular situations. The most common restriction is on the right to authorize the withholding or withdrawal of ANH. At the very least, many states require that patients specifically state that their agent is empowered to make decisions about artificial nutrition in order for the agent to have that right (see section on advance directive legislation, below).

Values Histories

If living wills are too vague, instructional directives offer the illusion of precision, and surrogate decision-makers may be uninformed about the wishes of the patient, perhaps a more elaborate statement of preferences would be helpful. The values history is essentially a more comprehensive and nuanced version of the original living will; it is a philosophical statement about what matters to the patient near the end of life rather than an intervention-specific document.[19]

Values histories enable a person to say that he would not want to suffer and to clarify that in particular he would not want to be hungry or thirsty but do not typically address medical interventions such as feeding tubes or IV fluids. They can be useful in helping a surrogate decision maker figure out what approach to treatment is most appropriate in a given situation. Individuals may also find the process of completing a values history useful as a way of helping them think through their own beliefs. They may then be in a better position to complete an instructional directive.

Combination Directives

Given the weaknesses of each of the existing advance care planning instruments, some people have advocated use of a combination directive that incorporates brief versions of each of these into an integrated document. One of the most widely used such combination directives is *The Five Wishes*, distributed by *Aging with Dignity*, which is recognized in 37 states.[20]

The *Five Wishes* is far less legalistic in tone than many other advance directives. It begins by naming "the person I want to make decisions for me," which is effectively a healthcare proxy designation. Then it indicates "what kind of medical treatment I want," which is essentially a brief instructional directive. In this section, 3 discrete scenarios are presented: being close to death, being in a coma and not expected to wake up or recover, or having "permanent and severe brain damage and not expected to recover." For each situation, the individual is asked whether he would want life-sustaining treatment, which is defined as "any medical procedure, device or medication to keep me alive. Life-sustaining treatment includes medical devices put in me to help me breathe; food and water supplied by medical device (tube feeding); cardiopulmonary resuscitation (CPR); major surgery; blood transfusions; dialysis, antibiotics; and anything else meant to keep me alive." Thus, in the *Five Wishes* formulation, patients select either aggressive care or purely palliative care, and ANH is an integral part of aggressive care.

The last 3 sections of *The Five Wishes* in effect constitute a values history. They address "how comfortable I want to be," "how I want people to treat me," and "what I want my loved ones to know." The "comfort" section is marginally more medical than the following parts, focusing on accepting interventions for depression, nausea, shortness of breath, hallucinations, and dry mouth. The concluding components allow the person to select from a menu of options, indicating whether he would want to die at home, have his hand held, have friends pray at his bedside, and then state that he forgives those he has hurt, asks for forgiveness from others, and conveys wishes for peace.

Other combination directives exist as well. The Vermont Ethics Network designed such a document years ago and periodically updates its form.[21] Because they seek to include multiple different facets of advance care planning, they necessarily simplify each of the components. Characteristically, they follow the example of the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT) study (the most extensive and influential empirical study of end-of-life

care in America)[22] and distinguish between maximal medical care on the one hand and purely comfort-oriented care on the other. ANH are regarded as part of maximal care.

Legal Underpinnings of Advance Care Planning

The principles underlying advance care planning are well established in American biomedical ethics and in US law. Patients have the right to determine what is done to their bodies and can therefore participate in medical decision making, as asserted by Justice Benjamin Cardozo in the case Schloendorff *vs* Society of New York Hospital in 1914. This right applies regardless of what disease the patient has and independent of what specific intervention his physician proposes. The patient does not need to be dying, and the treatment can be any medical intervention, from blood transfusions to ventilators to PN. Although the preponderance of opinion is that ANH constitutes medical therapy, there continues to be controversy surrounding this view. The Supreme Court supported this position in the Cruzan case, ruling 5 to 4 that artificial nutrition is medical therapy and that patients, or their surrogates speaking on their behalf, have the right to refuse any and all medical treatments.[23] To refuse treatment, a patient must be of sound mind, understanding the risks and benefits of treatment when she chooses to accept or to forgo therapy. If she is not decision-capable, the decision about treatment devolves upon a surrogate decision maker, ideally someone selected by the patient for this role.

In an attempt to facilitate advance care planning, the federal Patient Self- Determination Act was passed in 1990.[24] This legislation mandates that any healthcare facility that receives federal funds, whether a nursing home, hospital, or clinic, ask patients whether they have an advance directive. If they do, the facility is obligated to ensure that the directive is included in the patients' medical record; if they do not have such a directive, the facility is supposed to offer to provide information about advance care planning. Facilities are specifically prevented by law from *requiring* that patients complete an advance directive. The states, in turn, have each developed their own advance directive laws. Although all 50 states and the District of Columbia have some sort of healthcare proxy legislation, there are limitations on the power of the surrogate decision maker in various states. In addition, 37 states plus the District of Columbia have surrogate decision laws that specify a default proxy if the patient has not chosen his own representative.[25] Additional limitations exist on the power of these default proxies and these limitations, too, vary from state to state. In no area is there more variability, and are there more restrictions, than the arena of ANH.

A review of the advance directive legislation in each state found that 13 states specifically restrict the power of the healthcare agent to make decisions about ANH.[26] In Alabama, Kentucky, Missouri, Nebraska, New Hampshire, Ohio, Oklahoma, Oregon, Pennsylvania, South Carolina, South Dakota, and Wisconsin, the proxy has the right to authorize withdrawal or withholding of ANH *only* if the patient specifically indicated that his power extended to this arena. In New York, by contrast, the patient must state explicitly what his wishes are with respect to tube feeding and IV fluids, and proxies must adhere to those wishes.

Another study found that 20 states have 1 or more statutory provisions delineating a separate and more stringent standard for ANH than for other medical interventions. This can take the form of higher evidentiary standards or a requirement for preauthorization (as in the above examples); it can also take the form of requiring a qualifying medical condition (eg, imminent death) or a second medical opinion.[27]

The Supreme Court in the Cruzan case indicated that individual states could pass laws specifying the evidentiary standards for limitations of life-sustaining treatment. Whether requiring different standards for different forms of treatment will withstand legal challenge remains to be seen.

Physician Orders to Limit Care

Advance care planning instruments are intended to help prospective patients think in advance about what they would want done if they became seriously ill and were unable to speak for themselves. They all have to be translated into practice once a person actually becomes sick. Ultimately, the translation process takes the form of a physician's order (Table 2).

Probably the first and certainly the most widely discussed specific order to limit treatment is the "do not resuscitate" (DNR) order. Such orders became widespread after a scandal in the state of New York in which healthcare providers were surreptitiously indicating that patients should not undergo CPR by affixing a colored dot to the medical record without prior discussion with the patient or surrogate about his preferences.[28] Subsequently, procedures were established for actually writing a DNR order or, as it is sometimes more accurately called, a "do not attempt resuscitation" (DNAR) order. Perhaps surprisingly, >30 years after the first such orders were written, there continues to be uncertainty on the part of physicians about the circumstances in which the order takes effect and whether it refers exclusively to cardiopulmonary resuscitation (it does) or to other life-sustaining treatments (it does not).[29] Despite the confusion surrounding its use, the DNR order has been the model for other orders to limit treatment. Another even more ambiguous order is "comfort measures only," which is sometimes written even when a patient requests some life-prolonging treatments but not others. In the realm of

Table 2
Inclusion of artificial nutrition and hydration in physician orders to limit patient care

Type of order	Application	Inclusion of ANH
Do not resuscitate	Hospitalized patients with life-limiting illness	None
Comfort care	Patients being transported, none by ambulance	None
Levels of care	Nursing home residents	Typically includes 1 level limiting ANH
Let me decide		
Scope of treatment orders, transferable across institutions	Residents of specific state, especially nursing home residents	Special section on ANH
POLST (Oregon)		
POST (West Virginia)		

ANH, artificial nutrition and hydration; POLST, physician order form for life-sustaining treatment; POST, physician order for scope of treatment.

nutrition and hydration, orders can be written such as "no tube feeding" or "no IV fluids."

Other physician orders to limit care have been designed for use in nursing homes, to facilitate portability to other settings, and to distinguish between reversible and irreversible disease.

Levels of Care

Rather than writing individual orders for each of a variety of medical interventions, physicians sometimes find it useful to group interventions into levels of care. This has the advantage of facilitating the translation of advance care planning into physician orders to limit care. It also encourages physicians to broach the issue of specific interventions by speaking more broadly about the goals of care. Typically, physicians propose 4 or 5 alternative levels, depending on the goals of the patient.

In the schema devised for use at the Bedford Veterans Administration (VA) Hospital dementia special care unit, there are 5 possible levels. Level 1 reflects the primary goal of life prolongation. Maximal medical therapy is to be used, including CPR, intensive care unit treatment, and ANH. Level 2 includes the same aggressive care except for CPR. Level 3 excludes CPR and transfer to the acute hospital for management of intercurrent illness. Level 4 excludes CPR, hospital transfer, and antibiotic treatment for life-threatening infection. Level 5 excludes CPR, hospital transfer, antibiotic treatment, and also tube feeding.[30]

Let Me Decide

Another variant on the levels of care system that was designed and tested in Canadian nursing homes is the Let Me Decide system. This approach was subjected to a randomized, controlled trial and found to enhance patient and family satisfaction, as well as decrease healthcare expenditures and the use of aggressive medical treatment.[31] It asks patients to complete 2 separate advance directives, one in the event that they develop an "acceptable" medical condition and the other in the event that they develop an "intolerable" medical condition. Reversible pneumonia, for example, might be considered acceptable to many people, and severe stroke might be regarded as intolerable. In each situation, they are asked to make 3 distinct choices: a choice among 4 levels of care, a choice for or against attempted cardiopulmonary resuscitation, and a choice about feeding.

The levels of care are similar to those used at the Bedford VA Alzheimer's unit. They include *comfort care* (a focus on remaining warm, dry, and pain free, with no hospital transfers, IV treatments, x-rays, or antibiotics unless needed for comfort); *limited care* (excludes intensive care unit [ICU] care and invasive procedures but may include antibiotics, IV therapy, and hospitalization); *surgical care* (includes hospitalization and emergency surgery but no ICU care); and *intensive care* (no restrictions).

The section on feeding (to be completed for each of the 2 scenarios, acceptable and intolerable medical conditions) is quite detailed. It asks patients to specify whether they would want basic care, supplemental feeding, IV infusions, or tube feeding. Basic feeding is defined as being spoon-fed but having a regular diet. Fluids by mouth are to be offered, but there is no attempt to feed using a special diet, IV fluids, or tube feeding. If the patient does not choose basic feeding, he can then select supplemental feeding (supplements or special diets). He can also select IV feeding, defined as "giving nutrients, water, salt, carbohydrate, protein, and fat, by IV infusions." He is also asked whether he would accept tube feeding, either *via* nasogastric tube or gastrostomy tube.[32]

Physician Order Form for Life-Sustaining Treatment (POLST)

One problem with orders to limit care has been their lack of portability. Orders that are valid in a nursing home are not recognized by ambulance drivers or emergency room personnel. They need to be rewritten once a patient is hospitalized. To overcome this problem with implementing advance care planning, the state of Oregon developed a systematic approach to advance directives and orders to limit treatment.[33] The resulting form is the "POLST." Printed on bright pink paper, the form is

valid in all Oregon healthcare institutions, including nursing homes, ambulances, emergency rooms, and acute care hospitals. The original document is supposed to travel with patients as they move from one location to another.

The POLST form has 5 sections. First, it indicates whether the patient is or is not to have cardiopulmonary resuscitation, clarifying that this refers only to attempts made to revive an individual who is pulseless and without respirations. Next it specifies the chosen level of care, which it categorizes as *comfort measures* (wound care, suction, oxygen, no transfer to the hospital unless needed to control suffering); *limited medical interventions* (cardiac monitors, medications, but no intubation or mechanical ventilatory support, transfer to the hospital if medically required but avoidance of intensive care units); and *full treatment* (any indicated intervention). The third section of the POLST form addresses antibiotics in order to remind patients, families, and physicians that antibiotics are a form of life-sustaining treatment. The fourth section deals with artificial nutrition, stating specifically that this applies only if patients cannot take fluids by mouth. Finally, the orders must be signed, like any physician order, and the physician needs to state with whom the orders were discussed and on what basis the decisions were made.

Recently, a modified version of the POLST system was adopted by West Virginia. Known as POST, Physician Orders for Scope of Treatment, it is a simplified version that draws on the Oregon experience. It includes the same 5 sections as the POLST form. Of note, the section on ANH specifically states that, "oral fluids and nutrition must be offered if medically feasible." The order provides 3 choices for the use of IV fluids: no IV fluids, IV fluids for a trial period, or IV fluids to be given long term. It has a parallel set of choices for tube feeding.

Talking to Patients and Families

Advance care planning involves far more than merely completing a form, whether an advance directive or a physician order form. To truly capture the preferences of a patient, good advance planning must start by explaining to the patient and his proxy his current health status. Patients need to know whether they are robust, frail, demented, or dying *today* before they can contemplate what approach to medical care would make most sense for them if they develop a new medical problem *tomorrow*. Once they have a sense of their general condition, they can engage in the process of prioritizing their goals of care. Only then can they think about whether they favor life prolongation at any cost, a focus exclusively on comfort, or treatment geared to maximizing their quality of life.[34] Once the goals of care have been established, articulating specific wishes for particular situations often follows naturally. This is especially true for patients who already have a major, life-limiting condition with known, expected complications, such as chronic obstructive lung disease or amyotrophic lateral sclerosis (where respiratory failure is likely to develop) or Alzheimer's disease or cancer (where swallowing difficulties or anorexia commonly occur).

When physicians and patients discuss ANH as part of the advance planning process, they need to be clear on what it involves. Misconceptions about PEGs abound. Whether the physician is talking about tube feeding because it is a possible response to a present medical problem or a potential intervention down the line, she must explain what tube placement entails and enumerate the risks of the procedure. It is essential to describe the long-term complications of a PEG tube. Most important, the physician must explain the consequences both of having a tube and of not having one. For the case of advanced dementia, for example, the physician must explain to the surrogate (or the patient if this is a theoretical discussion about a possible future state) that gastrostomy tubes have not been shown to prolong life, nor have they been demonstrated to prevent aspiration pneumonia or pressure ulcers, other common problems in demented patients that they have sometimes been alleged to affect. And most important of all, there is no evidence that patients with advanced dementia or advanced cancer who have lost interest in eating experience suffering.[35]

Often the issue of hydration must be discussed separately from that of nutrition. Patients and families often associate lack of nutrition with "starving to death" and simultaneously believe that dehydration is exquisitely painful. In fact, dehydration is typically analogous to a natural anesthetic and allows patients to become progressively more somnolent until death arrives.

Conclusion

ANH have come to occupy a prominent place in advance care planning. Patients' preferences regarding the use of ANH are often spelled out in advance directives, particularly instructional directives, but sometimes in living wills and values histories as well. When a prospective patient designates a healthcare proxy, the individual is often asked to state whether the proxy has jurisdiction over decisions about ANH. State statutes and court cases reflect, and in some cases shape, the inclusion of ANH as a technology that is often an important part of advance planning. Finally, physician orders to limit treatment, an increasingly prevalent way of determining the scope of future care, typically address ANH, either by specifying a level of care that in turn either includes or excludes ANH, or by indicating directly whether it is to be provided.

As we engage in advance care planning with our patients or implement previously completed plans, we must remember that for patients and their fam-

ilies to make informed choices, they need a good understanding of just what ANH is and what it can accomplish. We need to be sure that patients grasp what is entailed by PEG tubes, both in terms of the procedure itself and subsequent risks and benefits. We need to be certain that we are familiar with the data on the efficacy of ANH in a variety of specific situations, such as amyotrophic lateral sclerosis, metastatic cancer, or advanced dementia. And above all, we need to be able to explain to patients what they can expect to *experience* in terms of pain and suffering, hunger and thirst, with and without ANH.

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