NON-ORAL HYDRATION AND FEEDING IN ADVANCED DEMENTIA OR AT THE END OF LIFE

GUIDELINES FOR PHYSICIAN STAFF
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PURPOSE OF THESE GUIDELINES

The public is increasingly concerned that death not be artificially prolonged. Of particular concern to patients, families, physicians, nurses and other staff, are guidelines about the responsible, ethical, and legal use of artificial hydration and feeding in patients who are dying.

These guidelines provide a framework for decision-making about the use of non-oral feeding and hydration in patients who are dying, taking into consideration medical, legal and ethical principles, cultural and religious values.

DEFINITIONS

Non-Oral feeding--provision of food by nasogastric tube (NG), gastrostomy tube (G-Tube) or Gastro-jejunostomy (G-J tube) or Total Parenteral Nutrition (TPN).

Artificial Hydration--provision of water or electrolyte solutions by any non-oral route (intravenous, hypodermoclysis, NG/G/GJ tube)

Advanced Late Stage Dementia or "Brain Failure"--a progressive, terminal illness, caused by one of a number of conditions including Alzheimer's disease, cerebrovascular disease, congenital or acquired neuro-degenerative diseases, brain tumors, AIDS, Parkinson's diseases, etc.; Diagnostic features include**;**

- Loss of higher cognitive function including memory and judgement;
- Loss of intelligible speech;
- Inability to interact meaningfully with family/friends;
- Inability to maintain oral nutrition due to loss of swallowing reflex;
- Inability to ambulate;
- Increasing need for medical attention due to complications of dementia;

Natural History [5] — **progressive dementia is a terminal illness**; when patients can no longer eat, speak or ambulate, the median survival is approximately 6-12 months, depending on the level of medical intervention for intercurrent illnesses (e.g. urosepsis).

IDENTIFYING THE DYING PATIENT –

Who is dying; How can this population of patients be identified? There are two groups of patients who can be thought of as dying: 1. Patients entering the Syndrome of Imminent Death, and 2. Patients who have a progressive, incurable, fatal illness.

1. Syndrome of Imminent Death

The *Syndrome of Imminent Death* (SID) is the final common pathway to death for virtually all patients except those dying from a sudden catastrophic event (e.g. acute MI). SID is characterized by the following stages:

Early Stage: bed bound; loss of interest and ability to drink/eat; cognitive changes: either hypoactive or hyperactive delirium, or sedation.
Mid Stage: further decline in mental status--obtunded; "death rattle"--pooled oral sections that are not cleared due to loss of swallowing reflex; fever is common.
Late Stage: coma, cool extremities, altered respiratory pattern--either fast or slow, fever is common;
Time Course: The time to traverse the various stages can be less than 24 hours or up to 14 days. Once entered, it is difficult to accurately predict the time course, which may cause considerable family distress, as death seems to "linger".

2. Progressive, incurable chronic medical condition

Patients in this category can be thought of as dying when most of the following features are present:

A. A progressive disease that no longer responds to life-prolonging treatments:
- Heart failure or COPD that is refractory to all medications;
- Metastatic cancer that is growing despite chemotherapy, with no further available treatments;
- Chronic aspiration pneumonia in the setting of dementia where the patient/surrogate have declined use of artificial feeding.

B. Progressive decline in functional ability.
- Increasing need for medical attention with little improvement in functional ability (ability to do self-cares, mobility);
- Increasingly frequent ER visits, hospital admissions;
- Steady weight loss.

C. Psychological acceptance of imminent death
- A major depression is excluded.

DATA CONCERNING THE MEDICAL EFFECTIVENESS OF NON-ORAL FEEDING / HYDRATION IN ADVANCED DEMENTIA AND/OR IN THE DYING PATIENT[3-5]

Benefits --- Psychological benefits for family members and caregivers include:

- Maintaining appearance of life-giving sustenance
- Maintaining hope for future cognitive improvement
- Removal/avoidance of guilt about making a decision to withdraw/withhold non-oral feedings.

Unproven benefits --- There is no medical evidence to confirm that provision of non-oral feeding or hydration in patients with late-stage dementia will meet the following goals:

- Reduction in aspiration pneumonia
- Reduction in patient suffering
- Reduction in infections or skin breakdown
- Improved survival duration (in a population of similar patients)

Burdens
- Risk of aspiration pneumonia is the same or greater than without non-oral feeding

- Increased need to use physical restraints
- Wound infections, abdominal pain and tube-related discomfort
- Cost; Indignity

ETHICAL PRINCIPLES

1. There is no medical or ethical mandate to provide non-oral feeding/hydration to a dying patient when the burden/risk of feeding is greater than the benefit.
2. Non-oral feeding/hydration is considered a medical treatment, not "ordinary care". "Ordinary care" includes provision of oral food and water, bathing, dressing, keeping a patient safe, warm and comfortable.
3. The decision to withhold or withdraw non-oral feeding/hydration in this setting is **not euthanasia** (the active administration of a drug/procedure by a physician to induce death);
4. The decision to withhold or withdraw non-oral feeding/hydration in this setting is **not assisted suicide** (the provision of a lethal drug/procedure to a patient, with their full knowledge that the drug/procedure can be used by the patient to induce death at the time/place of the patient's choice).
5. Patients who do not have decision-making capacity (non-decisional) may have non-oral feeding/hydration withdrawn or withheld in the following situations:
   - If the patient has indicated approval of withholding/ withdrawing food on a valid Wisconsin advance directive (POAHC or Living Will) and the physician feels that withholding/withdrawal will not incur added suffering or;
   - If the patient is in a Persistent Vegetative State (PVS) or;
   - If the patient has no advance directive but had expressed *clear evidence* in the past that they would not want non-oral feeding/hydration continued and/or if the burden/risk of feeding/hydration is greater than the benefit;

RELIGIOUS/CULTURAL VALUES CONCERNING FOOD/WATER

1. The act of eating and the provision of food to the sick are important cultural symbols signifying life and hope. Thus the withdrawal or withholding of food often appears contrary to normal societal values. Families will often mistakenly equate withdrawal or withholding of food with *starvation, euthanasia or murder*.
2. Many, but not all, religions recognize that death is a normal aspect of life and that non-oral feeding/hydration may be discontinued when the burden exceeds the benefit. However, this is not a universally held religious belief; when in doubt, clinicians should consult with the hospital chaplain staff or spiritual leader.
3. Physicians themselves have deeply held cultural and religious values surrounding the issue of feeding. Such personal feelings must be respected, but not allowed to interfere with the presentation of all reasonable facts and options to families or surrogate decision-makers.

INFORMATION FOR PHYSICIANS WHEN COUNSELING FAMILIES OR SURROGATE DECISION-MAKERS.

Alternatives to non-oral feeding

When a decision is being made to either discontinue non-oral feeding or not to begin such feeding, alternatives do exist:

- Hand-feeding, using food/liquids prepared in such a manner that will lessen the aspiration risk (e.g. thickened liquids); or
- No oral or non-oral food, with the expectation that death will result within 14 days;
  Note: There is no data that withdrawal/withholding of non-oral food from patients causes suffering when adequate comfort measures are instituted.
  Note: The dying patient typically has no or little appetite, moreover ketosis will blunt the symptom of hunger. Moistening the lips and good mouth care will alleviate the symptom of a dry mouth. There is good data that provision of non-oral hydration, by itself, will not correct the symptom of dry mouth among the terminally ill. [9]
- Aggressive comfort measures will always be provided;

  ⇒ Pain and symptom management
  ⇒ Moistening agents to lips and mouth
  ⇒ Frequent change of body position
  ⇒ Family support

Discussions with family and surrogates—Key Points

1. An advance directive should be completed by patients at the earliest onset of a chronic fatal illness. Once completed, physicians are legally obligated to follow the patient's expressed wishes.

2. Once a medical determination has been made that adequate oral nutritional intake to sustain life is not possible and there are no prior expressed wishes, all reasonable options must be discussed with families/surrogates.

3. The option of withholding/withdrawing feeding must be done *in a manner that minimizes guilt upon the family/ surrogate.*

   - If available, review patient wishes expressed in an advance directive with family/surrogate; **Note**: if a patient has expressed wishes not to have non-oral feeding/hydration in an advanced directive, emphasize to the surrogate(s) that they do not need to make the choice about withdrawal or withholding as the choice has already been made by the patient; the decision by the surrogate is about *honoring* a previously made decision.
   - Inquire about patient and family religious or cultural values;
   - Ask the family/surrogate, "what would (name) want if he/she could tell us?";
   - Give permission to withhold/withdraw feeding—patients/families/surrogates will be looking to the physician for clear permission and leadership to make this decision;
   - Offer consultation input (Palliative care, Ethics, Chaplaincy, Psychology);
   - Offer families/surrogates time to make a decision; suggest they contact their spiritual leader, friends or other family for further discussion;
   - Provide patient/family with education material;

4. If a decision is made to begin non-oral feedings, establish a time frame (e.g. 4-8 weeks) for re-evaluation, to establish if the goals of feeding are being met

(e.g. weight gain, improved function). Reassure families/surrogates that if goals are not being met, non-oral feeding can be discontinued.

5. If a decision is made to discontinue/not begin non-oral feedings, and hand-feeding is not an option (e.g. diminished level of arousal), and intravenous hydration is not started, families/surrogates should be advised that death will likely ensue within 14 days and that all comfort measures will be continued.

Discussing Artificial Feeding/Hydration—Suggested Phrases

- *I am recommending that the (tube feedings, hydration, etc.) be discontinued (or not started); this treatment will only prolong his/her dying, it will not improve their quality of life.*
- *Your (relation) will not suffer; we will do everything necessary to ensure comfort.*
- *Your (relation) is dying from the (insert terminal disease); they are not dying from starvation.*
- *Almost all dying patients lose their interest in eating and drinking in the days to weeks leading up to death; this is the body's signal that death is coming.*

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