

“Matters of the Heart...”

Feeding and hydration in palliative care

By Elizabeth J. Latimer, MD, CCFP, FCFP

Matters related to hydration and feeding for people in a palliative situation present dilemmas and challenges for families, doctors, health-care teams and patients themselves. The central question is how best to treat the person, and the goal is to ensure comfort and peace of mind for all concerned.

Why “matters of the heart”? The issues surrounding these two aspects of care (feeding and hydration) are rather more complex than other treatment decisions because of the large component of emotion and heartfelt angst over what is most kind and appropriate for the patient. The role of food and water as being central to sustenance, kindness and mercy makes feeding and hydration quite different than other treatments, which can more readily be seen as medical or scientific and, therefore, can be declined. Understanding the matters of the heart (the

large emotional, intuitive and feeling part of these decisions) helps us understand why decision-making about fluids and food is often less straightforward than in other areas. This article will explain the



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Case 1:

Mr. K, aged 86 years, has suffered a massive stroke. Neurological assessment and a computed axial tomography (CAT) scan reveal he is unlikely to survive beyond a few days. If he does, he will be in a severely compromised state. After discussing this with his family, goals of care are “comfort measures only.” He has an intravenous running.

Questions:

Should the intravenous be continued?

Should feeding be considered?



Case 2:

Mrs. D, aged 32 years, is dying of a brain tumour. She is unresponsive and is no longer able to take in food or fluids. She has an intravenous running. The nurses are suggesting that this be stopped. Her family cannot agree with this, saying: “Then we would be killing her. She would die of thirst.”

Question:

What is the wisest approach to care?



issues involved and present an approach to assist in making these types of care decisions. Each patient and family clinical situation is unique. The guiding question is “What is best for this particular patient and family in this particular situation?”

Four areas which are relevant to making decisions about feeding and hydration are considered in this article:

- The underlying philosophical and ethical foundations that inform these decisions;
- The types of hydration and feeding to consider;

- The concept of formulating goals of care as an aid to decision-making; and
- Approaches to helping patients and families decide. A patient and family information sheet is provided at the end of this article.

Philosophical Considerations

Decisions about whether and how to give patients food and water raise deeper issues relat-

Case 3:

Mr. P, aged 84 years, is recovering from aspiration pneumonia. He has advanced Parkinson's disease and can only swallow bits of food, not enough to nourish him. The question of a per endoscopic gastrostomy (PEG) feeding tube has arisen. The family is worried that he isn't eating enough and the staff worry about further aspiration.

Question:
What to do?



Cases 4 and 5:

Mrs. J and Mr. M, both in their mid-fifties, have advanced cancer of the esophagus and are no longer able to consume sufficient nourishment or fluids. The health-care team considers the role of PEG tubes for feeding.

Question:
How might decisions be made?
What is the best treatment for each person?

ed to values and philosophy. Important questions emerge, such as:

- “What is our philosophy about life and death?”
- “What constitutes life or meaningful life?”
- “What do we understand about suffering and what do we consider as being in a state of suffering?”
- “Does continued life in greatly reduced circumstances necessarily constitute suffering? For whom?”
- “Does continued life in greatly reduced circumstances have meaning and for whom?”
- “Under what circumstances should artificial feeding and/or hydration be stopped, continued, or never started?”

These are complex questions, but health-care teams, patients and families must discuss and reflect upon these issues. Such discussion will help us to understand the differing viewpoints, beliefs and values that bear upon a particular patient's care.

Food and water are known to be central to survival. Thus, decisions not to hydrate or feed may be felt to be decisions not to foster survival. This may be the source of the distress people feel when they need to make these decisions, which carry a great burden of responsibility.

The offering and sharing of food and drink are important parts of social, political and life-passage ceremonies in all cultures. It is a way of relating and connecting to one another, and is often at the foun-

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Case 6:

Mrs. K has advanced breast cancer and is being treated for pain with a hydromorphone subcutaneous infusion pump at 12 mg per hour and bolus prn doses of 6 mg per hour. Her family brings her to the emergency room because she hasn't been taking fluids in the past 48 hours and "her muscles are jumping." You notice she is a frail woman, somewhat sedated, who exhibits quite severe multifocal myoclonus. The previous week, she had been well enough to go out for a car ride.

Question:

What is happening to Mrs. K?

What is the role of hydration?



dation of religious rites. As a result, food and water may seem necessary to support frail, injured and dying people. Feeding others is considered morally required, kind and compassionate.

Doctors and health-care team members should also be aware of the powerful imagery of hunger and thirst as they are reflected in our art, drama and language. Phrases such as "dying of thirst" and "starving to death" reflect this deeply pervasive belief. Regrettably, such phrases also may be used by insensitive health-care providers and misguided friends whose values differ from those of family members. "You are starving her" is a phrase that creates enormous distress and doubt about the plans for care and treatment in palliative care settings.

Ethical Principles That Inform Care

Beneficence (doing good) and respect for autonomy are two important guiding ethical principles. We want to respect patient choices in these matters and to foster "the good" for them. Nonmaleficence

requires that we "do no harm" and justice requires that we treat the patient and family with fairness.¹ The meaning of the patient's wishes, good and harm, will vary with each situation. They can be best understood in the context of the goals of care for the patient. Figures 1 and 2 present ways of thinking about goals of care and treatment approaches.¹ As with all patient care, the process of eliciting and establishing goals of care with patients and families depends on skilled and sensitive interpersonal communication. "Truth with tenderness" is the guiding principle when giving and exchanging information.² Goals of care provide the framework upon which decisions to feed or hydrate patients can be assessed.

Physical Aspects of Hydration and Feeding

Do artificial feeding and hydration prolong life in patients who are dying of other causes, or does the cause of their dying take pre-eminence and proceed despite these? The answer to this largely depends on how close the patient is to death and the progressive

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nature of the disease. If a patient is actively dying or near death, artificial hydration and feeding will not play a significant role in prolonging life. This can be assuring to families. The situation is less certain if patients have a progressive illness, but are not near death or dying. In such situations, hydration and feeding may prolong life to an appreciable degree. Such prolongation can be a benefit or a burden to the patient, depending upon his/her goals of care and wishes in the matter.

Does lack of food and fluid cause pain, discomfort or hunger in medically ill people? Although the answer is not known with absolute certainty, available knowledge suggests that it does not.³⁻⁵ Fastidious care of the mouth, lips and nares, however, is an essential prerequisite to our ability to say this with any confidence. While we can inform

patients and families about this knowledge, their “matters of the heart” related to feeding and hydration may take more prominence than the actual “science” of the situation. We must be prepared for this.

Methods of feeding include oral, nasogastric tube feeding, PEG tube feeding and parenteral nutrition by peripheral or central routes. Methods of hydration include oral, intravenous and subcutaneous (hypodermoclysis).⁶⁻⁹ When we consider feeding and hydration, we are really talking about two approaches: natural “per oral” food and fluids or feeding and hydration by “artificial means” (*i.e.*, by using technology). This distinction can be helpful. A further beneficial distinction is the difference between sufficient intake for comfort and peace of mind of patient and family *versus* optimum intake of food and fluids with the goal of prolonging life. The

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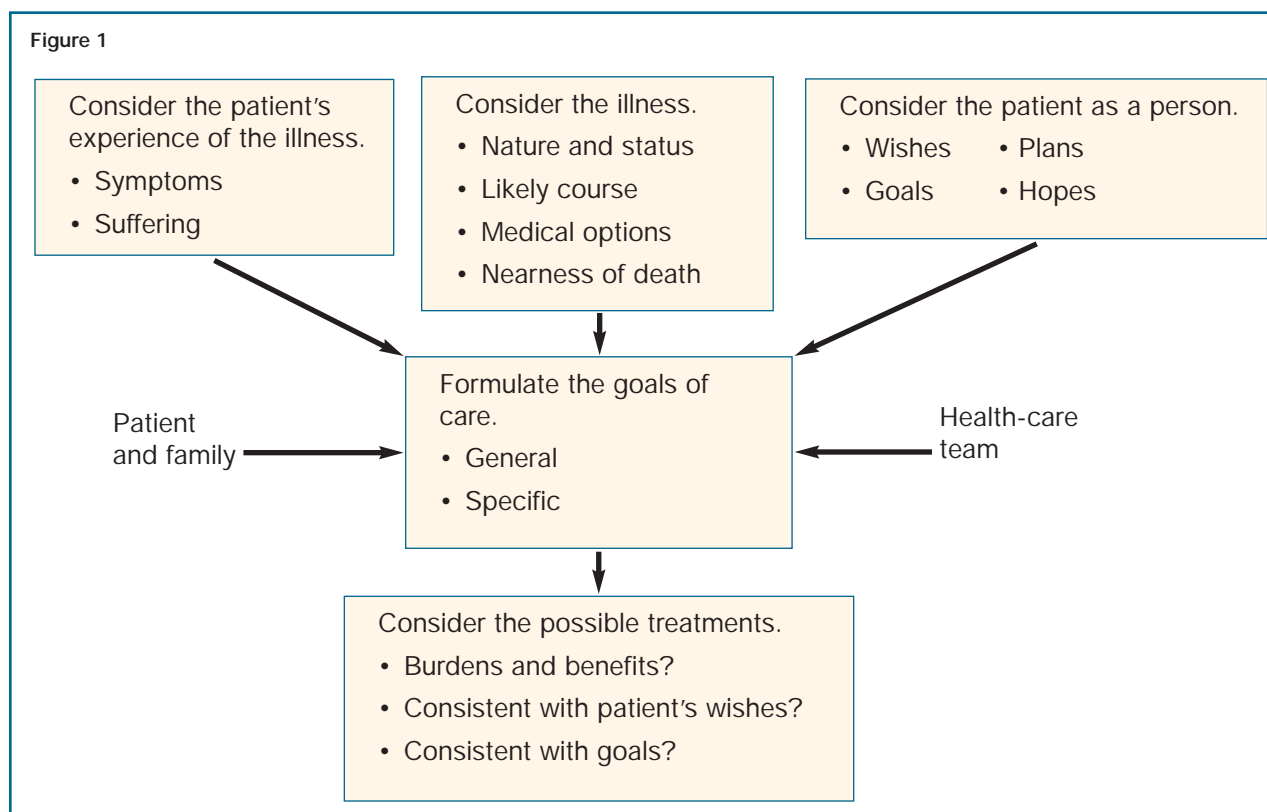


Figure 1. An approach to formulating the goals of care and treatment plans for seriously ill and dying patients. Reprinted, with permission of the publisher, from: Canadian Medical Association: Ethical care at the end of life. Can Med Assn J 1998; 158(13): 1741-7.

ability to achieve the former may reduce the pressure on everyone to provide the latter.

Benefits and Burdens

The potential benefits of hydration and feeding may include enhanced strength and well-being, enhanced peace of mind for both patient and family, and enhanced symptom control, including alertness, reduced confusion, a moist mouth, *etc.* The burdens of hydration and feeding may include the necessity of intravenous or central lines, laboratory tests and the risk of aspiration with tube feeding (nasogastric

and PEG). For certain patients, such as those with lung cancer or end-stage heart failure, artificial hydration and feeding may actually increase suffering through increased chest congestion from additional water in the lung and cardiovascular system. Similarly, increased third-spacing of fluid, resulting in peripheral edema, anasarca, ascites and pleural effusion, will lead to increased body discomfort and dyspnea. In some situations, the technologies involved in artificial feeding and hydration may limit the choice of care setting for the patient and family.

The Decision-Making Process: Assessing the Patient's Situation

Formulating answers to the following questions is a helpful guide:

- What is the nature of the patient's primary diagnosis? How advanced is the disease condition? What is the physical status of the patient and what is the expected prognosis?
- Is there a superimposed illness causing deterioration? Is it treatable and if so, what will be the overall outcome for the patient?
- What are the goals of care for the patient? Are they understood by the patient, family and health-care team?
- How near is death, given your consideration of the above questions?
- What means of feeding and hydration are being considered? What is the goal or purpose? What are the risks and benefits?
- What is the benefit/burden ratio of the approach being considered for this particular patient? Do the benefits outweigh the burdens?
- Is the patient competent to make decisions about care? If yes, what are his/her wishes for treatment? If no, are his/her prior and present wishes known? Is there an advance directive previously completed?
- What are the wishes and views of the family? What is their role in decision-making? Do they support the competent patient or do they speak for the patient who lacks the capacity to decide?
- Are there religious or cultural values held by the patient and family that influence decisions about feeding and hydration?
- What are the views of nursing, medical and other staff?

Step Two: Talking With the Patient and Family

In considering the above questions, the physician and health-care team will determine one or more possible approaches to the patient's care. It is now time to talk with patient and family.

The process of this discussion is to seek consensus on the issues and plan of care.¹⁰ Decisions may be reached in one meeting, but more commonly, several conversations may be required. Patients and their families may need time to consider the options.

The steps in the discussion include:

- Establishing the understanding of patient and family about the illness situation.

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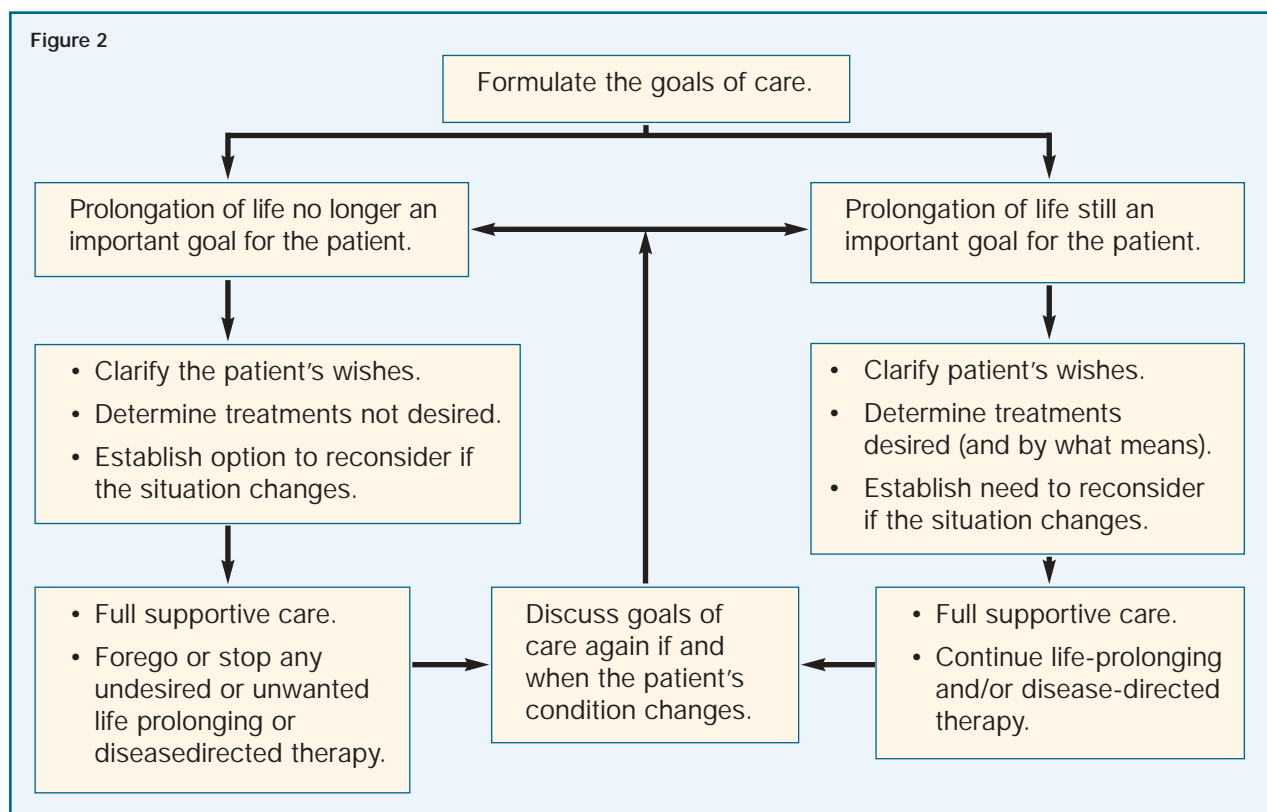


Figure 2. Patient's wishes for prolongation of life: an approach to decision-making and care.

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- Affirming this and giving new information when required.
 - Providing an opportunity for the patient to describe his/her understanding of the situation and his/her goals and wishes about treatments. The family may describe this for the patient who cannot speak for him/herself. An advance directive may be part of this discussion.
 - Presenting the possible approaches to matters of feeding and hydration, taking the above information into account.
 - Reaching consensus on the approach to care.
 - Planning for follow-up conversations between patient/family/health-care team.
- If the patient has the capacity to decide, his/her wishes in treatment decisions will prevail. If the patient lacks that capacity, the family may speak for the patient. It is helpful to guide the family in conveying their loved one's wishes by asking questions such as: "Do you have a sense of what your father would have wanted in this situation?" An advance directive and durable power of attorney, if available, will give the family and health-care team guidance when making decisions.

Discussion of Case Studies

The following scenarios illustrate how decision-making can unfold in clinical care. Each patient and family situation is unique.

Case 1. In Mr. K's situation, intravenous fluids do not play a major part in his ability to survive his stroke and the decision to discontinue would depend on the wishes of the family, with a goal of giving them peace of mind. The health-care team ensures an excellent, regular mouth-care program is in place for the patient's comfort and that his family receives attentive emotional support. The team establishes goals of care that are "comfort care only" (Figure 1), and discuss with his adult children their feelings about hydration and feeding, including giving them the Patient Information Sheet at the end of this article. At first, Mr. K's family wishes to continue the intravenous, saying "This is all such a shock. We would worry that he is thirsty." After three days, however, they have had some time to come to terms with the situation and see no improvement in Mr. K's condition. They request the intravenous be discontinued. Mr. K passes away peacefully, with his family at his side, three days later. They feel at peace about their decisions for their father.

Case 2. With Mrs. D's family, the team provides the same information and approach to care as with Mr. K. The family understands that the fluids are not food and are not necessary for her comfort. However, they also have matters of the heart: they feel that she will be thirsty without the water and that they would cause her to die sooner by discontinuing the intravenous. Mrs. D's husband's peace of mind is very important. He will need to grieve his wife's death

for many years and needs to be able to feel at ease with the way her care was given. The intravenous fluid is continued at a moderate rate of infusion until her death two weeks later.

Case 3. Mr. P's situation is not uncommon. Fortunately, he is able to indicate his wishes in the matter and asks for "no feeding tubes." A swallowing assessment is done by the speech language pathologist. He can swallow small portions of foods, such as ice cream, pudding, soft purée and some fluids. Nursing staff and family members are taught how to feed him in a safe manner. Both he and his family are relieved he can consume small amounts of food by mouth. They understand this is "palliative feeding," the goal of which is patient comfort and the family's peace of mind. They agree that when he is no longer able to have oral intake, there will be no intravenous or feeding tubes, as per his wishes.

Cases 4 and 5. Mrs. J is enjoying quality of life. She is pain free with medications, is able to walk and enjoys going out. However, she can no longer eat. She wants to try the feeding tube to see if it helps her feel stronger, and, if not, would like to have it

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removed. The potential benefits of PEG tube feeding outweigh the burdens for her, given her wishes and her stage of illness.

Mr. M is more ill than Mrs. J. He is jaundiced, cachectic and bed-ridden. He is peaceful within himself: "I am ready to go, doctor. I just want to be comfortable here at home. No tubes for me, doc." Given his wishes and stage of illness, feeding tubes would not further his goals of care.

Case 6. Mrs. K, although very ill, had been enjoying some quality of life until the week before you see her, at which time she became sleepy and restless and reduced her oral intake of fluids. She is exhibiting some signs of opioid excess and may be dehydrated and have hypercalcemia. You discuss this with her family and learn that Mrs. K still has goals of care for treatment of potentially reversible problems, although she has asked for "no CPR." Laboratory studies reveal dehydration and hypercalcemia. Intravenous treatment is undertaken and her hourly hydromorphone dose is reduced to 8 mg, with a bolus prn dose of 4 mg. As her sensorium clears, you find it necessary to gradually increase this medication again to manage her previously controlled pain.

Conclusion

Decisions about feeding and hydration with patients who have advanced illness are unique to the individual patient and family situation. The context is the stage of the illness, the goals of care and the wishes of those involved. Decisions in this area are heavily influenced by deeply held values, beliefs and emotions, which can best be considered "matters of the heart." Careful assessment and sensitive conversations with the patient and family often reveal the most appropriate path to treatment. CME

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Suggested Readings

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