

# Love Without Food: Supporting Families' End-of-Life Care Decisions for Critically Ill Late-Stage Cancer Patients

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## Article abstract

In some families, there is an inseparable connection between showing love, caring, and providing food. These conceptual connections can create tension between families and care teams over end-of-life care for critically ill late-stage cachexic patients with cancer when families demand that their loved one receive feeds. This case study describes how to dissolve these tensions without compromising the family's values or the medical team's ethical duty of nonmaleficence.

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ÉTUDE DE CAS / CASE STUDY

# Love Without Food: Supporting Families' End-of-Life Care Decisions for Critically Ill Late-Stage Cancer Patients

Amitabha Palmer<sup>a</sup>

## Résumé

Dans certaines familles, il existe un lien inséparable entre le fait de montrer de l'amour, de prendre soin et de fournir de la nourriture. Ces liens conceptuels peuvent créer des tensions entre les familles et les équipes soignantes au sujet des soins de fin de vie pour les patients atteints de cancer en phase avancée de cachexie et gravement malades, lorsque les familles exigent que leur proche soit nourri. Cette étude de cas décrit comment dissoudre ces tensions sans compromettre les valeurs de la famille ou le devoir éthique de non-malfaisance de l'équipe médicale.

## Mots-clés

bioéthique, soins contre le cancer, soins de fin de vie, éthique clinique, cachexie, nutrition, cas difficiles

## Abstract

In some families, there is an inseparable connection between showing love, caring, and providing food. These conceptual connections can create tension between families and care teams over end-of-life care for critically ill late-stage cachexic patients with cancer when families demand that their loved one receive feeds. This case study describes how to dissolve these tensions without compromising the family's values or the medical team's ethical duty of nonmaleficence.

## Keywords

bioethics, cancer care, end-of-life care, clinical ethics, cachexia, nutrition, difficult cases

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## CASE

From the beginning, the patient's wife and three adult children took charge of the goals of care conference involving the medical team. The spouse provided the medical team a detailed assessment of her interpretation of the cause and solution to her husband's stay in the Intensive Care Unit (ICU). According to the family, it was simple: their loved one needed food.

Just over a week prior, the patient, in his late 50s, had aspirated while receiving tube feeds on the main floor. He had originally entered the hospital to receive nutritional support while fighting end-stage progressive metastatic lung cancer. A month previously, he had stopped eating at home. Now he lay intubated and unconscious in the ICU. Complicating matters, an MRI revealed that he had experienced silent epileptic events but left uncertain his neurologic status and the possibility of recovery, even if he could eventually be extubated.

The patient's wife and one of the sons appeared to dismiss the concerns raised by the team and instead fixated on the nutritional status: the patient had only received an IV drip since entering the ICU. If only he could receive proper nutrition, they reasoned, he would gain the strength to regain consciousness and possibly receive more treatment. Such a recovery would allow the family to realize the patient's wish to die at home. The family implored the team to try feedings again.

The medical team unanimously believed that the appropriate course was to transition the patient to comfort care. Their view followed from the conjunction of the patient's advanced cancer, extreme weakness, uncertain neurological status, inability to tolerate feeds, and unlikelihood of ever being extubated. Ethically, the team was concerned that continued aggressive measures in light of the patient's full code status would cause more harm than good. In particular, restarting feeds offered little possibility of benefit and high risk of harm due to aspiration.

## ASSESSMENT

This is not an uncommon scenario when an ethics consultant is requested to facilitate a discussion between the medical team and the family of a critically ill patient with terminal end-stage cancer. The family's fixation on feeding signaled that the differences between starvation and cachexia had not been adequately explained. *Cachexia* is a secondary disease in patients with cancer causing progressive dysfunction. It is characterized by a systemic inflammatory response, negative protein-energy balance, and involuntary loss of lean body mass, with or without a decline in adipose tissue (1). Unlike starvation or malnutrition, cachexic patients experience decreased appetite and feeding will not reverse the symptoms (2).

There are very good medical and ethical reasons not to feed critically ill end-stage cancer patients.

1. The body enters progressive organ failure. This implies that the digestive systems are no longer able to metabolize nutrition. Feeds will just sit in the body causing painful bloating and, possibly worse, sepsis (3). The patient will suffer more than if they had not eaten and their remaining time can be shorter than it otherwise would have been.
2. Fluid from the blood accumulates within body cavities, intestinal areas, or areas of the body that normally contain little fluid. This is called “third spacing.” When the kidneys start to fail, fluids build-up in the body causing significant discomfort, and fluid can enter the lungs making breathing difficult (4).
3. Most importantly, perhaps, is the fact that end-stage patients with cancer do not feel hungry. So, while it’s natural to be concerned that a loved one is suffering from hunger, they are not in fact. Regarding thirst, applying a moist sponge to the lips and tongue is generally sufficient to alleviate any discomfort (2).
4. Finally, in this patient’s case, there was already a significant background risk for aspiration as he met three of the five criteria for elevated aspiration risk: Cognitive impairment due to stroke, gastronomy tube, and pulmonary disease requiring ventilation (5).

While the above may be common knowledge for ICU staff, for many families, the conceptual and moral connections between feeding, caring, and love are tightly intertwined. For such families, a doctor’s injunction not to feed is unintelligible. It is extremely difficult to grasp that feeding your loved one will harm them. It’s harder still to watch them waste away while the medical staff insists you not feed or, sometimes, even hydrate them.

## PRACTICAL STEPS FOR DISSOLVING THE CONFLICT

In cases like the one described here, the following practices are recommended for clinical ethicists: First, clinical ethicists must be alert to – and perhaps even assume – confluences of starvation with cachexia and strong tendencies to associate feeding with love and care. Acknowledging and then addressing these beliefs can mitigate family disagreements with the medical team and amongst each other, reduce family distress, and avoid unnecessary suffering to patients. Once the clinical ethicist identifies this gap in knowledge they should, when possible, defer to the relevant expert to provide the explanation. In this case, the palliative care doctor was asked if she could explain the difference between starvation and cachexia, and whether that distinction might be relevant to the patient’s care.

We cannot expect deeply held beliefs and commitments to be overturned in a single encounter. Nevertheless, the palliative care doctor’s kind and patient explanation tempered the wife’s enthusiasm for tube feeds. This allowed the ethicist to introduce two other important tools: a time limited trial and managing expectations. The team and the wife were able to agree that the patient would receive the minimal possible feeding, and only during the day when there were sufficient staff for continual monitoring, and they would cease feeding upon any counterindication. This would lower the risks into an acceptable range for the team while offering the possible benefits the family sought in the context of the patient’s uncertain neurological prognosis. Finally, the ethicist elicited the team’s prognosis in order to avoid discord that can arise later from unrealized, unrealistic expectations.

Sadly, the patient did not absorb the feedings, and on the fourth day they were discontinued. Two days later, the patient passed away.

## HUMANISTIC AND ETHICAL MEDICINE

A humanistic approach to medicine acknowledges the fundamental affective and moral interdependence of human lives and so aims to treat the patient *as well as* the family. But treating the family should never be at the expense of the patient. Had the team followed the family’s initial demands for aggressive feedings, they would have violated the final caveat. But denying any feedings at all risked failing to treat the family. Recognizing and filling the gaps in knowledge allowed the team to practice humanistic medicine. It allowed the family the peace that comes from knowing that they did everything possible to honor their loved one’s wish to die at home. It allowed the team to uphold their ethical duty to protect the patient from unreasonable risk. And finally, although ultimately unsuccessful, it provided the patient every medically possible means of realizing his own wish to die at home.

## DISCUSSION QUESTIONS:

1. If the MRI had revealed anoxic brain injury such that there was no chance of neurological recovery, would minimal feeds have been humanistic and ethical medicine? Why or why not?
2. Suppose the patient hadn’t expressed any preferences for where they wanted to die. Would this have changed what constitutes an ethical plan of care? Why or why not?
3. Suppose the patient’s only legal next of kin were two adult children. One son wants the time limited trial for minimal feeds while the other “does not want to prolong dad’s suffering and dying.” Instead, he wants to transition to comfort care only. What should the care team do in this situation? Why?

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Aucun à déclarer

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**Conflicts of Interest**

None to declare

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