Food & Water
An End of Life Perspective

“All they talk about is food, always wanting more to eat. Can’t you make them understand that I’d eat if I could?”

“He’s not eating a thing. I feel like I’m letting him starve. What can I do?”

Every terminally ill patient experiences loss of appetite and weight loss, and almost every family member sees food and water as a source of nurturing, caring and comfort. While family members become focused on insisting the patient eat even when the patient says “No”, the patient is rarely very concerned about loss of appetite. This conflict can be emotionally painful to patient and family, leading to conflict and stress as the disease progresses.

In every Palliative Care program, nutrition is an issue that will be dealt with at every nursing visit and, as with other aspects of care; nutrition involves physical, psychosocial and spiritual issues. The goal of Palliative Care is to educate the patient and family and to prepare you for the changes that will occur as the disease progresses, to explain why these changes occur, what options for care are available, what the outcome of interventions is likely to be, and then to support the decisions you make.

Concerns related to nutrition and hydration are emotionally charged. You need to know that loss of appetite and weight loss are a part of the disease progression of terminal illnesses and the dying process. While medical treatments are available to relieve many symptoms experienced by end of life patients, there is little to offer in halting or reversing loss of appetite and weight loss. The human body has many ways of adapting during the dying process, and reduced interest in food and water is one of nature’s strategies that allow the patient to die more peacefully and comfortably.

The effects of food and water will change through the early stages to the final stages of a terminal illness. In the early stages, it is appropriate to encourage the patient to eat and drink and to offer favorite foods in small quantities frequently throughout the day. It is not realistic to expect the patient to eat and drink the same amount as they used to. A small glass of juice and a few bites of food may be considered a meal. High calorie/ high protein recipes from books on cancer may be used with caution. While the recipes may be appropriate for some cancer patients, they are not likely to be palatable to a terminally ill patient who has lost interest in food. The patient is the best judge of the foods that are appropriate to serve. As the disease progresses, continuing to encourage the patient to eat and drink may cause both physical and emotional discomfort and will not significantly increase the patient’s life expectancy.

When the patient simply refuses to take food, family members usually feel personally rejected and frustrated in their role of nurturing and caregiving. You may feel
angry because the patient has “given up” and “would get stronger if only they would eat.” The fact is that the patient not eating is a constant reminder that death is the ultimate outcome. Please express your feelings and fears to us. We will help you to identify the ways in which roles have changed because of the patient’s inability to eat and to explore the ways of expressing nurturing and caring. If the conflict over food continues, the patient can feel guilty as if they are disappointing their family and may try to force themselves to eat, even if it makes them physically uncomfortable. The guilt may go so far that the patient also begins to believe that they are not trying hard enough to get stronger and they have failed their family in some way. Some patients will simply refuse to eat or drink anything as a way to exert some control in a situation where they feel that they have lost control or to force the family to accept the reality of the disease progression.

The Palliative Care team feels that it is important to dispel your fears about pain and discomfort caused by the reduced intake of food and water. We also need to share information and discuss the options of (intravenous) IV fluids and tube feedings. We have had extensive experience with the patients who stop eating and drinking as death approaches. Many studies have also been done comparing the comfort of patients who chose not to have IV fluids or tube feedings and those who chose to have them.

Both our experience and the studies show that dehydration, caused by decreased or no oral intake of fluids, does not cause discomfort if care is given to prevent dryness of the mouth. Some patients have reported feeling euphoric or having an increased sense of wellbeing. The drowsiness caused by dehydration may itself be beneficial. Dehydration may increase comfort by reducing stomach secretions, which cause nausea and vomiting. When dying patients are not receiving IV fluids or tube feedings, there is also less buildup of fluids in the lungs, eliminating the need for suctioning. The placement of IV needles and the need for family members to monitor IV fluids can cause stress and discomfort for both patient and the family. It is necessary to weigh quality of life against quantity of life -- possibly a few hours or days -- if IV fluids are used.

The body’s ability to digest and use food changes in the later stages of terminal illness. Liquid supplements through tubes in the nose or directly into the stomach cannot be expected to result in weight gain or to significantly lengthen life. Palliative Care has cared for patients receiving these feedings. The patients continued to lose weight and, in many cases, developed problems that created discomfort such as nausea, vomiting, diarrhea, or gastric distention. As with IV fluids, a tube must be placed in order to deliver liquid food to the body, and the family must manage and monitor closely to prevent displacement of the tube. Again, quality vs. quantity of life must be measured.
An essential part of the hospice philosophy is that death is a natural process. Hospice is founded on the belief that the body adapts as a disease progresses and death approaches, and that these adaptive processes should not be interfered with unless there is clear evidence that benefits to the patient will outweigh any discomfort. Hospice also believes that the patient and family have the right to make choices regarding care. Palliative Care team members will provide you information, facilitate discussion regarding these difficult decisions, help explore concerns and feelings, and help clarify values as part of the decision-making process. The ultimate decision must be made by the patient and family. Once the decision is made, it will be the Palliative Care team member’s role to give their support to that decision.