APPENDIX

Making Choices About Nutrition and Hydration

As a nurse who has spent many years in long-term care, I have seen many families struggle with making the decision to withhold nutrition and hydration in a loved one who is terminally ill. It is never an easy task! I will make an attempt to help you look at every aspect of this decision-making process in the hope this will make that decision just a bit easier.

Allowing an individual to decide to withhold nutrition and fluids when a quality of life no longer exists can be a tough decision to make. Feeding tubes and intravenous fluids can be traumatic and invasive. A decision can be made however, to die naturally and without such artificial means.

What Is Artificial Nutrition and Hydration?

Artificial nutrition and hydration is a type of treatment used to maintain life through the placement of an invasive device (tube) into an individual's veins, nose (the tube goes from the nose into the stomach), or intestine. Liquid food or intravenous fluids are then administered. This form of feeding is given to an individual who cannot eat or drink naturally. This type of feeding can be provided for a short time when a return to a normal quality of life is expected. However, this has also become a treatment for individuals who no longer have quality left to their lives. An example of this type of individual may be someone with end-stage Alzheimer's disease, or an individual who has suffered a severe stroke and can not speak or swallow and has lost total function of one side of their body.

Why Do We Feel We Need to Give Food and Fluids?

Nutrition has deep symbolism in all societies. It begins with the very beginning of life, with a mother caring for a child in her womb and it carries over to the mother feeding at her breast. When we give food we give life to another human being. People consider eating and feeding a symbol of caring, loving, and a deep sense of communion with another human being.

Our Lives Are Centered Around Food

We feel a need to share what we have with others and when we entertain we serve food and drinks. We offer coffee and drinks when someone visits. We can pick up the spirits of a friend by going to lunch. Eating together can send a message that we care. Family events are often centered on food, such as holiday celebrations and birthdays.

Things We May Ponder When a Loved One Is Terminally Ill

Will my family member endure more pain and suffering without food and fluids?

The answer is no. Most terminally ill patients will die within 3 to 14 days of stopping nutrition and hydration, depending on their condition when food and fluids were stopped. This is usually a peaceful process and the patient seems unaware of it.

Studies indicate that feelings of hunger and thirst are generally not apparent when someone is dying. When offered food or fluids, these individuals will take very little. If the patient does experience any hunger or thirst, he or she only wants a very small amount. Thirst can be managed with ice chips, a favorite beverage, hard candies, or frequent oral care to moisten the mouth.

Will continuing food and fluids have disadvantages in the terminally ill?
Fluids increase the amount of urine produced. This may result in the insertion of a catheter, or may require the painful movements of being placed on a bedpan. There may also be a need for movement to change and clean the bed and patient because of urinary incontinence. Food and fluids also increase gastrointestinal activity, causing abdominal distention, nausea, vomiting, and diarrhea. These conditions will only increase pain and discomfort.

Will adding fluids increase respiratory secretions?
Yes, giving fluids may have this effect and often, near the time of death, an individual has difficulty controlling oral secretions. Adding fluids may cause aspiration pneumonia, coughing, congestion, or difficulty breathing. Aspiration pneumonia is often a terminal event.

The aspiration of regurgitated stomach contents (due to tube feedings) is generally more dangerous and painful than the aspiration of food from swallowing. All of these symptoms may necessitate oral suctioning (mechanical removal of oral secretions such as phlegm)**,** which is traumatic and irritating. Medication may also need to be prescribed to dry up these extra secretions, potentially adding more complications for someone who already may have difficulty swallowing.

Does dehydration cause suffering?
Studies have shown most dying patients rarely complain of feeling thirsty. It is quite common for people to drink less in the latter stages of life, because of low energy, reduced awareness, lack of appetite, and difficulty swallowing. There is often a definite lack of interest in fluid intake in an individual who is dying. If patients are placed in a hospital and are given fluids, they often suffer from fluid overload. They may have abdominal distention and fluid retention in the lower body or legs which can cause even more discomfort and often can cause increased pain.

While intravenous fluids can supply water, sugar, and vital electrolytes, a deeper intravenous catheter (placed surgically) is necessary to provide fat or protein, the building block of tissue. Without protein, your loved one is likely to develop bedsores despite the finest nursing care.

What can result from inserting tubes?

Placement of tubes, whether in the stomach, intestines, or veins can be irritating and painful. Continuous intravenous therapy requires frequent insertion or reinsertion of intravenous needles or surgical placement of a more permanent intravenous device. All of these devices can restrict the activity and movement of the patient even more.

What Do We Classify as Technology or "High Tech"?

So where do we draw the line? Do we burden the patient with tubes or do we spend quality time on providing comfort?

Healthcare professionals often think that giving someone tube feedings or intravenous therapy is a form of basic, humane care that is no different than providing a clean bed. There have been many debates over whether this type of treatment is considered "extraordinary" or "ordinary" care. It is not so much the type of technology, but whether the benefits outweigh the burdens from the technology. It actually has been proven that more harm is done and the patient suffers rather than receiving any real benefits.

Life support is any artificial or mechanical means of maintaining life for an individual who would die without its use. Life support involves machines, instruments, tubes, and drugs. Life support can postpone death but it does not cure. Rather, life support maintains normal bodily functions until the patient's body has recovered from an illness, which is considered reversible. Life support, therefore, should only be provided when someone has a reversible illness.

Questions we can ask... Do the benefits of the type of life support being considered ou-weigh the consequences? Will the use of life support result in an acceptable quality to the patient's life?

What About Controlling Pain?

Pain control is a top priority for the terminally ill person To achieve the best quality of life for patients, we must be able to control pain. If pain is caused by the disease process, a large amount of narcotic pain medication may be required to manage the pain. It may even be necessary to increase the dosage of the narcotic to relieve pain, even if this hastens the death of a patient. Because alleviating pain and suffering is the primary goal, large doses of narcotics are a common and effective way to provide comfort.

Another concern often focuses on possible addiction to the narcotic medications. However, at the end of life, the only form of abuse is failing to relieve the patient’s pain. The dying patient’s symptoms should determine the best dosage of medicine to control his or her pain.

Who Is This All About?

For everyone involved, putting the patient's wishes first is most important, and at the same time, meeting the patient’s need for comfort and pain relief. This is often difficult for the family, who must deal with the loss of a loved one. It is also difficult

for healthcare providers, who must change their usual caregiving routines to meet the needs of the individual patient. This process involves switching from aggressive care to comfort care, while focusing on providing emotional support and compassion.

How Do Patients Make Their Wishes Known?

One way the patient can make their wishes about end-of-life care known is through a document called an advanced directive. If directives are planned, both the clinician and the patient can have a clear, open discussion about the patient's wishes. The patient's advocate will also have a clear picture when making decisions, if previous discussions have taken place. With an advanced directive, it is the patient who is first and foremost who makes the choices.

How can a family deal with the guilt? Remember that withholding nutrition and hydration is not "starving " or "killing" the patient. It is not the withholding of nutrition and hydration, but the disease that is the cause of the impending death. The team of professionals will be available to help you answer any questions or concerns throughout this difficult time.

In Conclusion

The decision to forego life support is never easy. It is clear that we have struggled for a long time with appropriate ways to use our technology and at the same time deal with the results of technology. We must consider quality of life and we must respect the decision that a loved one has made. The patient's wishes should direct care at the end-of-life.

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