



Any person who has been involved in an end-of-life situation with a loved one knows that there are many difficult decisions that require the loving consideration of many factors. When families struggle with these decisions, mediation can be helpful because of the strong emotions that often bubble up.

A skilled mediator can assist family members in their decision-making by acknowledging emotions and allowing issues that are beneath the surface to be addressed. There are always opportunities for healing, increasing the dignity of everyone involved, and fostering love and often forgiveness among family members.

A common difficult end-of-life decision arises when a loved one is unable or unwilling to meet his or her own basic nutritional needs. Sometimes this situation is caused by physical issues that impact the patient's ability to chew, swallow food, and to drink. Other times, chronic illness, medication side effects, fatigue, or weakness overcome the patient's desire and ability to eat and drink. In some cases the patient may be comatose and unable to eat or drink and incapable of participating in decisions regarding their artificial nutrition or hydration decisions. The result is that the individual simply does not take in sufficient nutrition to meet the basic needs of his or her body. The person begins to waste away without medical intervention.

This situation is especially painful to family members who often know and visualize their loved one as a vigorous and healthy

Mediating End-of-Life Decisions:

Feeding Tubes and Other Quality of Life and Care Choices

By Louise Phipps Senft and William Senft

person; watching him or her lose weight and descend toward death frequently triggers an urgent desire to "fix the problem."

Enter the physician—trained in healing and skilled in "fixing" the problems of the human body. Physicians have many means to solve patient problems with medication and surgery. Many physicians focus their attention on any means at their disposal to heal the patient and maximize the chance of a cure. In situations where a patient is unable to meet nutritional needs, the physician may suggest putting the patient on a form of artificial nutrition—the "feeding tube."

The feeding tube is inserted into the patient's stomach and pumps nutrition into his or her digestive system. With the feeding tube, the patient's body will have its nutritional needs met and there is the hope that the patient will regain strength, recover from the underlying illness, and achieve a full recovery. There is the chance that, if there is no recovery from the underlying illness, the patient will suffer indefinitely as life is continued with artificial nutrition. What many families do not realize is that it is a very difficult decision to remove a feeding tube once it is inserted because it may compromise an individual's chance of surviving.

Should the food tube be inserted? Some patients and families, if they are informed and aware of the consequences, struggle mightily with this question. Others are denied the opportunity to evaluate the consequences and the benefits as they are rushed along in the ordinary course of hospital care. On the one hand, insertion of the tube may be absolutely necessary for any hope of a turn around, and on the other hand, insertion of the tube may prolong suffering and lead to a more difficult, painful decision later—when and whether to remove the tube.

Who makes this initial decision? The patient always is the first decision maker. There is much confusion about the role

of an advanced health care directive or “living will.” Typically these legal documents express the desire of the patient to choose whether to have extraordinary measures taken to prolong his or her life with medical intervention. An individual may designate a third party to act as their agent to make medical decisions on his or her behalf when the patient is unable to express their decision.

This situation also raises the issue of capacity—even though physically able—can the patient understand what he or she is being asked to decide? Is the patient mentally capable of making the decision? Family members and physicians may have very different views on this issue, and capacity and decision-making authority are legal issues often decided by state laws.

Moreover, the laws of various states differ. New York and Missouri, for instance, require “clear and convincing” evidence that a patient lacking in capacity would choose to refuse artificial nutrition and hydration. Mediators are well advised to understand applicable law when working with clients facing these decisions.

A mediator or other person skilled in assisting patients and families, such as a hospital chaplain, nurse or social worker, and who also may be trained in conflict transformation and how to provide opportunities for informed decision-making, can be helpful to families and patients. Such a person can help by slowing things down so that perspectives and input can be considered and discussed openly by giving those with concerns an ability to speak and be heard.

Dialogue among the patient and family members can help achieve clarity and often leads to healing, forgiveness and love, as the patient and family members face mortality and consider a lifetime of experiences and dynamics that have defined the relationships. The spiritual dimension of the relationships almost invariably begins to surface. The patient’s sense of the purpose of his or her life, the way he or she wants to face death, and what death means from a spiritual perspective, may need to be explored to gain clarity in making decisions. Many of these choices often do not have the chance to emerge when decisions are hurried and forced to be made in the context of medical emergencies, illness, and family crisis.

One constructive approach is to consider and discuss these issues before facing them in the hospital or nursing home. A family meeting, with a mediator’s assistance, to discuss how to handle difficult end-of-life medical decisions, is beneficial to each person involved. It also is an opportunity to discuss any number of other issues that face families as parents and other family members age.

Sometimes older people are caught up in disagreements between family members or other loved ones over what care or other arrangements are seen as appropriate for them. This can make an older person’s life uncomfortable as they try to avoid siding with one child or the other. It may even happen that the views of the older person are not even sought by the family members who become, understandably, either caught up in their roles providing a parent’s care or who defer to others to decide for them.

In mediation, the views and preferences of the patient, when able to participate, may be invited before others speak, or in a separate confidential meeting, so that the older person can talk without having to be in the position of disagreeing with others. Any differences of perceptions and opinions between siblings, in the presence of or outside the presence of the parent,

.....
A family meeting, with a mediator’s assistance, to discuss how to handle difficult end-of-life medical decisions, is beneficial to each person involved. It also is an opportunity to discuss any number of other issues that face families as parents and other family members age.

.....
can be discussed and better understood without influencing the older adult in ways that may compromise his or her true choices and preferences.

With the opportunities possible in the mediation process, facing the death of a loved one can become a celebration of the life infused with what matters most to every family member. ☺



Louise Phipps Senft and William Senft left private practices as litigation and transactional attorneys to found Baltimore Mediation in 1993, a firm specializing in transformative mediation training and facilitated dialogue approaches to problem-solving for families and businesses stuck or in transition. Voted “Baltimore’s Best” Mediator by Baltimore Magazine in 2002, Ms. Senft’s work in elder care mediation was the featured story on “ABC World News with Charles Gibson” on July 27, 2007. For more information, please visit www.baltimoremediation.com.