

## **To Help You Make A Decision About Tube Feeding<sup>1</sup>**

Before they are seriously ill or approaching death, some individuals have completed a health care proxy and living will, and discussed their wishes at great length with a health care spokesperson. In these cases, the health care spokesperson may have a clear understanding of the person's preferences regarding tube feeding. However, in many cases the patient or the health care spokesperson is unclear about what choice to make. At that point, all of the benefits and burdens of tube feeding over eating or drinking by mouth need to be considered so an informed decision can be made.

### **Eating At the End of Life**

In all cultures and throughout all history, offering food has been a sign of caring and hospitality. Our mothers made sure we were well fed. Most people enjoy eating with family and friends, especially on special occasions. In most religions, food is part of sacred rituals. It is no wonder, then, when someone we love is unable to eat and drink naturally, that we feel compelled to "feed" them in some way. It seems to be basic caring.

But, as death approaches, you will not "keep up your strength" by forcing yourself to eat when it makes you uncomfortable. If eating is a social event for you, or providing food is one of the common ways of expressing caring in your family, your loss of appetite may be distressing to you and your loved ones. You might enjoy small amounts of home-cooked food, dishes that mean something special to you. However, you should also know that a decrease in appetite is natural and eating less may increase, rather than decrease, comfort.

Because most dying people are more comfortable without eating or drinking near the end of life, giving food or liquids to them by tube feeding is usually not beneficial, especially if restraints (a tool that limits movement), IVs (used to supply fluids into your veins), or hospitalization are required.

The truth is, for those who are dying, the time comes when it might be more compassionate, caring, even natural, to allow a natural dehydration (loss of body water) to occur. Tube feeding and providing fluid through an IV can make the last days of their lives more uncomfortable.

### **Tube Feeding for the Stroke Patient**

Sometimes people who suffer a stroke cannot swallow at first and a tube is inserted to provide nutrition (food) and hydration (liquid). Sometimes these patients can learn to eat again, and the tube is eventually removed. Sometimes a patient with throat cancer might not be able to swallow after successful treatment of the disease. He or she may have a feeding tube and still carry on otherwise normal activities. Few would question whether feeding tubes are appropriate in cases like these. But there are cases where feeding tubes and IVs are more of a burden to the patient than a benefit.

## **A Trial of Tube Feeding**

Tube feeding, taking in food and liquids artificially, can be done for a period of time and then stopped.

If death is not expected in hours to days, you and your family may consider a time-limited trial of artificial food or liquid to see if it improves comfort, alertness, or energy. To give tube feedings for a short period of time, a tube is usually threaded through the nose into the stomach. For longer periods of tube feedings, tubes (called PEGs) may be placed through the abdomen directly into the stomach. A PEG tube may be placed in a patient by a gastroenterologist (stomach doctor) or surgeon, depending on the patient's other medical problems. Intravenous (IV) catheters, a different type of a thin hollow tube, are usually placed in the veins of the arm or hand to provide liquids. If IVs are going to be used for food as well as liquids, then larger IVs usually must be placed in the large veins of the arm, neck, chest, or groin (area where the thigh meets the hip).

You and your family should agree in advance with your doctor about what you hope to accomplish from being provided with artificial food or liquids. You should also determine, in advance, how long to wait to see if you are getting any better before removing the tubes.

The evidence from medical research and patients' bedsides suggests that it is often more comfortable to die without artificial liquids provided either by a feeding tube or into the veins. Until this generation, everyone who died a natural death died without artificially supplied fluids. Refusing food and drink has always been a sign of the last phase of serious condition leading to death. Only recently have people been afraid that not providing food and fluid through a tube would force someone to "starve to death." There is no medical or clinical evidence that not putting a feeding tube or IV into a person leads to a more painful death. In fact, the research says just the opposite.<sup>2</sup>

Without artificial liquids there tends to occur a loss of body water resulting in a dry mouth. Very few people feel any thirst. Dry mouth can be easily addressed with good mouth care, ice chips or a moistened sponge swab.

## **Tube Feeding and the Dementia Patient**

Increased difficulty with eating and swallowing is one of the signs that an Alzheimer's patient has moved into the final stages of the disease. An Alzheimer's patient may tend to choke on food and drink, running the risk of an infection affecting one's breathing. This person may lose interest in food or forget how to swallow. These signs mark the end of a very sad and long disease process. By this point the patient is often totally dependent on others for care, unable to go back and forth to the