

Education on Tube Feeding for Residents/Patients and their Representatives

The Problem

Many health problems may cause you to lose more and more of your mental and physical abilities. The problems may become so serious that you may no longer be able to eat all the food your body needs. Also, some conditions, such as stroke, Parkinson's disease, Alzheimer's disease, and other forms of dementia, may make it difficult to swallow, allowing food to go into your lungs. This can cause pneumonia.

Nurses or others can feed you, but you may still continue to have trouble eating and swallowing properly, and you may not be able to get all the food and fluids your body needs to maintain your health.



Treatment

Sometimes a speech therapist may be able to help you improve your swallowing ability. A change in the consistency of the food you eat may also be helpful. If these do not help, another treatment for eating and swallowing problems is to have a feeding tube placed into your stomach. You would be fed liquids through the tube which provide nutrition and fluids.

A feeding tube can be used temporarily for a few days if you become suddenly sick and unable to eat or drink. The tube would be put through your nose and down your throat into your stomach and you would receive liquid food several times per day. If you regain the ability to feed yourself, then the tube could be removed.

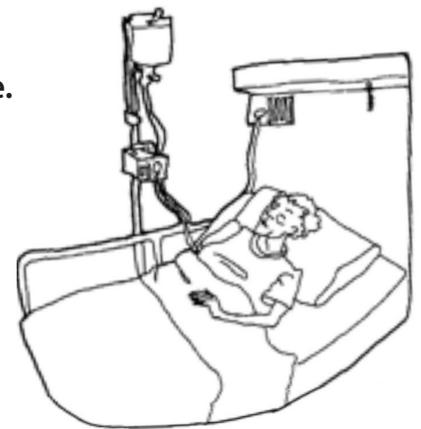
If a feeding tube is needed for longer than a week, it can be placed into your stomach. If you regain the ability to eat on your own, this tube could be removed.

In order to have the long-term feeding tube placed in your stomach, you would need a short operation that usually lasts less than an hour. You would be given medication to make you comfortable while the doctor makes a small cut in your skin so that the feeding tube can go into your stomach. This operation is usually safe and has been done often.

Your Choice

Feeding tubes are not used for everyone. You have a choice about whether or not you want this treatment. Feeding tubes may be used for a short time or for the rest of your life, and can be removed at your request or by the request of your health care decision maker. You should understand, however, that if you choose not to have a feeding tube, your choice will not affect any other aspect of your care.

All of your other treatments and care will continue.



(continued on reverse)

Education on Tube Feeding for Residents/Patients and their Representatives (cont'd)

Making the Decision about Tube Feeding

Many people make a decision in advance about whether or not they want tube feeding. You can choose between having tube feeding and asking for a 'No Tube Feeding' order. You may not be able to make this decision for yourself at the time you are unable to eat or drink. Making the decision in advance will help make sure that your wishes are carried out.

The decision whether or not to have tube feeding can be a difficult one. You may want to discuss it with your family, doctor, nurse, social worker, or a religious leader.

Understanding the benefits and risks of tube feeding is important when you make your decision. The chart below explains the benefits and risks of tube feeding.



Benefits of Tube Feeding

Tube feeding can provide you with nutrition and fluids on a temporary or long-term basis when you are unable to eat or drink, or have difficulty swallowing. However:

- Many research studies have shown that tube feeding does not prolong life, or improve function or quality of life.
- Research studies have also shown that tube feeding does not prevent episodes of pneumonia due to swallowing trouble, or the development or healing of skin wounds (pressure sores) that can be caused by not moving around and not having enough nutrition or fluid.

Risks of Tube Feeding

Although tube feeding can provide you with nutrition and fluids, there are several risks of having tube feeding. For example:

- Complications of the operation done to put the tube in your stomach, such as bleeding, infection, and pain can occur, but they are infrequent.
- The area around the tube can become irritated, painful, or infected.
- The tube may become blocked or fall out, requiring trips to the hospital to have it replaced.

Help in Making Your Decision

There are many resources available to you in making this decision. Organizations such as the American Association for Retired Persons, the Coalition for Compassionate Care, the Conversation Project, Closure, and Caring Connections of the National Hospice and Palliative Care Organization, as well as many others



have information available in print and on their websites that may be helpful to you.

In addition, most states have standard forms for documenting your decisions in advance ('Advance Directives'), and many are recommending completing an order form in advance, such as Physicians Orders for Life Sustaining Treatment ('POLST') or other similar forms.