



Fact Sheet: **Advanced Illness:** **Feeding Tubes and Ventilators**

Introduction

Families caring for a chronically ill loved one may eventually face very difficult decisions regarding medical treatment for the person in their care. The progression of many conditions—Alzheimer’s disease, Parkinson’s disease, Amyotrophic Lateral Sclerosis or post-stroke, for example—may lead to two of the most common such decisions: whether to use feeding tubes when a chronically ill person can no longer chew and swallow his or her food, and whether to use a ventilator when someone can no longer breathe on his or her own. Given that a person with a chronic illness may be ill for many years, caregivers might put off discussing and thinking about medical complications that are likely to happen in the future. When decline from an illness is gradual, it is easy to not notice the early warning signs of an impending medical crisis. But understanding and discussing these issues ahead of time can help avoid the need to make urgent decisions during a crisis.

Nutritional Supplement and Hydration

As many types of neurological illnesses progress, the muscles of the throat gradually cease to work properly. This can cause swallowing difficulties, gagging, choking, trouble coughing, loss of voice, or difficulty

catching one’s breath. Receiving proper nutrition is difficult if someone is having trouble swallowing, which is usually accompanied by eating less. The danger of choking while swallowing is that the food can “go down the wrong pipe”—in other words, the food is aspirated into the lungs. Gagging can also cause vomiting, which may cause some of the stomach contents to enter the lungs. All of these possibilities can lead to an illness called *aspiration pneumonia*, which occurs when bacteria causes infection in the lungs which have been damaged by food or stomach material.

Treating aspiration pneumonia usually requires a hospital stay and a course of antibiotics. Patients may be fed during hospitalization with an *NG Tube* (nasogastric tube, inserted through the nose and down the esophagus to the stomach), which allows the patient to receive liquid nutrition. If swallowing difficulties continue, physicians may discuss the use of a *G-tube* (gastric tube) with the family. Surgery is required to insert a tube directly through the front of the belly into the stomach and the patient then receives all or most of his/her nutrition via frequent “feedings” during the day and/or night. This feeding can be done by hand using a syringe or by using a machine that will drip the liquid through the tube into the stomach. Either way, the patient must be sedentary for a period of time in order to receive the food.

With or without feeding tubes, patients can learn swallowing techniques to reduce the likelihood of aspirating. Caregivers can also help by preparing “thick liquid” diets (thin cream of wheat, mashed potatoes, thickened broths for example), that are easier to swallow, and by avoiding thin liquids and things that require chewing. Some people can enjoy eating small amounts this way, even when they are receiving their primary nutrition through a tube.

In many cases, feeding tubes help prevent illness and prolong life. In diseases like ALS, feeding tubes can be a normal part of treatment, as swallowing may be compromised before a person is in the end stages of the disease.

If someone has trouble swallowing and continues to eat or drink, the possibility of repeated incidences of aspiration pneumonia is high. The decision then becomes how to treat the resulting pneumonias (see "ventilators" below). Some patients truly miss the taste and experience of eating and find normal eating hard to give up. Patients with dementia and/or severe agitation may pull at the tube and/or pull it out, which might require sedation or restraints. And remaining sedentary for the time required to receive the feedings may be difficult.

There is some debate, for example, about whether feeding tubes actually extend life in end-stage Alzheimer’s disease. For many, this is a quality of life issue, and they would prefer to not live this way. Depending on the situation, people receiving tube feedings may not be able to avail themselves of hospice services.

If the family chooses not to insert a feeding tube, the patient and family may have decided that this person is in the final stages of the illness, and that they are now willing to allow death to occur. If the person is

totally unable to eat and does not use a feeding tube, the body will slowly shut down over a period of one to two weeks. Comfort measures are given, so the patient does not suffer, and hospice care can help the patient and family.

Intravenous hydration is the process of giving fluids using a tube in the veins. In the past, IV hydration was used to prevent death from dehydration, which was considered a painful way to die. We now know that gradual dehydration is not painful; rather, it brings a lessening of awareness about discomfort, so that the person slides naturally toward death. If the body is shutting down, it cannot rid itself of the excess fluids given by IV and thus the fluid builds up in the lungs and leads to shortness of breath. Dry mouth is treated more effectively with good mouth care than by IV fluids. With hospice care, it has been the practice not to give IV hydration when someone is close to death. Naturally, pain and other symptoms are still treated as they occur. As with a feeding tube in the advanced stages of an illness, IV hydration can prolong dying rather than prolong living.

How Does One Make These Decisions?

When a person is diagnosed with a chronic and degenerative illness, it is important for the patient and family members to discuss these topics early in the illness, while the patient is still in a position to let family members know what his/her wishes are regarding these decisions—it is much more difficult to make a decision under the pressure of an acute episode. If the ill person has begun to choke when swallowing, it is a good time for the family, the patient, and, if possible, the physician, to discuss the “what ifs,” and how to think about the choices, keeping in mind the patient's values. Consultation with clergy may also be helpful. (It is important that our

loved ones know how we would come to a decision, remembering that decisions can be changed if needed, as none of us knows what we will really want until the time comes. Unfortunately, these decisions most often need to be made at a time when we can no longer state our preferences.)

See the fact sheets *Advanced Illness: Holding On and Letting Go* and *Holding a Family Meeting* for additional help.

Pneumonia and Ventilators

One of the other choices a patient or family member faces is how to treat pneumonia. Many years ago, pneumonia was called “the old man’s friend,” as many people suffering from chronic illnesses ultimately died of it. This is no longer true, due to modern medicine’s techniques to prevent and treat pneumonias.

Pneumonia, an infection involving the lungs, makes it difficult to breathe, causes pain, confusion and progressive weakness. There are two kinds of pneumonia—bacterial and viral. Bacterial pneumonia can be treated by antibiotics; viral pneumonia cannot. Aspiration pneumonia, the kind that can result from difficulty swallowing, is a bacterial pneumonia.

After a stroke or heart attack, or when a patient is in the final stages of an illness such as Alzheimer’s disease, family members and the patient can choose not to treat pneumonia if it occurs. In this case, comfort measures to reduce pain and the distress of labored breathing would be offered, but antibiotics would not be given. Some people recover spontaneously under these circumstances; others die within a week or two.

With bacterial or viral pneumonia, as with initial treatment for a stroke or heart attack or when breathing is compromised by illness, one of the possible treatments

involves a ventilator, a machine that helps the person breathe. A ventilator requires a tube down a person’s throat or through a tracheotomy (hole in the throat), also called intubating. When a person is put on a ventilator, it is not always known ahead of time whether it will be for a short or long term. Often a ventilator is used for a short time in treating pneumonia; the patient is then “weaned” off the machine and is able to breathe again on his/her own.

Sometimes, however, people are too weak, or their illness is so progressed that they will never be able to breathe again on their own. The patient then faces the possibility of remaining on the machine for the rest of his/her life. Even people who have not discussed end of life issues may have expressed the desire to not be kept alive “on a machine;” generally, it is a ventilator they are referring to when they say this.

When someone cannot regain the ability to breathe on his/her own, the patient and family may have to decide whether or not to continue using the ventilator. The decision to stop is very difficult to make and, in making it, you may feel as if you have chosen to “kill” the person. However, like the use of nutritional supplements, use of a ventilator is also a quality of life decision. For some people, staying alive under these circumstances is not acceptable. One way patients and family members can ease the difficulty of this decision is to choose not to use a ventilator as treatment in the first place. Patients can make their wishes known about this through *Advanced Directives* and discussions with their physicians and family members.

Even with the best advanced planning, patients and family members often must make decisions in a crisis situation. It is natural, even reflexive, to make decisions to prolong life. However, quality of life measures are also important considerations. Each illness has a different course and

being well informed about a loved one's particular illness can help with the decision-making process. When you know what the choices and consequences are, you can make a decision consistent with a loved one's wishes and values.

Credits

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Handbook for Mortals: Tube Feeding, www.growthhouse.org

"Palliative Excellence in Alzheimer's Care Efforts (PEACE)", *Journal of Palliative Medicine*, 4/6/2003, <http://www.ncbi.nlm.nih.gov/pubmed/12854952r>

Resources

Southern Caregiver Resource Center
3675 Ruffin Road, Suite 230
San Diego, CA 92123
(858) 268-4432 | (800) 827-1008 (in CA)
Fax: (858) 268-7816
E-mail: scrc@caregivercenter.org
Web site: www.caregivercenter.org

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions and is for residents of San Diego and Imperial counties. Services include information and referral, counseling, family consultation and case management, legal and financial consultation, respite care, education and training, and support groups.

Family Caregiver Alliance
235 Montgomery Street, Suite 950
San Francisco, CA 94104
(415) 434-3388 | (800) 445-8106
Web Site: www.caregiver.org
E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving

issues and provides assistance in the development of public and private programs for caregivers.

Alzheimer's Association

www.alz.org

Compassion & Choices

www.compassionandchoices.org

Hospice Foundation of America

www.hospicefoundation.org

National Hospice and Palliative Care Organization

www.nhpco.org

Dying Unafraid

by Johns, Fran Moreland

Published by Synergistic Press (1999-04)