

THE CAREGIVER'S GUIDE TO PEG TUBES FOR PATIENTS WITH DEMENTIA

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Most demented patients lose the ability to chew or swallow in the latter part of the disease. As the patient loses weight, the family must decide whether to insert a tube for feeding. Patients with swallowing problems may develop difficulties with choking or discomfort during feeding. These symptoms slowly appear in the later phases of the disease and appear to worsen after 6 or 7 years of intellectual decline. Abrupt onset swallowing problems suggests some other problem, e.g., stroke. Patients may develop feeding problems during episodes of temporary confusion from medical problems. Families may wish to insert a feeding tube to increase patient comfort, improve nutrition, reduce suffering, or simply out of frustration over inability to help the patient.

About Swallowing Problems:

Alzheimer disease and most dementias are deadly diseases that produce ongoing brain damage. Most demented individuals eventually lose the ability to walk, talk, chew, swallow, and control bodily functions like bowel or bladder. Although modern medicine can prolong the life of persons with dementia, doctors cannot maintain the quality of that life. Families must weigh the burden of suffering against the duration of life.

Families are often confused about feeding tubes and other aspects of end-of-life care. Some families choose to insert PEG tubes because of guilt, inadequate information, or worry that others will believe they let their family member die. Physicians often avoid discussions about the sad, painful subject of dying from dementia. Studies show that families rarely remove a tube once inserted into the patient. Family decision-making is easier when caregivers receive a complete description of the progressive brain damage from dementia, problems associated with PEG tubes, and the benefits of hospice care for Alzheimer patients.

Feeding tubes inserted through the nose or the mouth, called NG or nasogastric tubes, are not a reasonable option for long-term care. These tubes cause significant discomfort and produce serious medical complications such as pneumonia. Long-term feeding via the vein is not a

reasonable option because limited nutrition is provided and the veins soon become so damaged that the patient can no longer tolerate the constant sticking to insert the catheter.

About the PEG Tube:

The term “PEG” tube stands for percutaneous endoscopic gastrostomy tube. Percutaneous means the clinician must create a hole in the abdominal skin and muscles as well as a hole in the stomach. Endoscopic means that a viewing tube is inserted through the mouth into the stomach to guide the feeding tube into place. The insertion of a PEG tube requires sedation of the patient and a surgical procedure. A flexible tube, i.e., endoscope, is threaded into the patient’s stomach through his mouth. A second tube is inserted through the skin and muscles below the rib cage on the left side and through the space between the abdominal muscles and the stomach called the peritoneal space. The tube is then punched into the stomach cavity. The PEG tube is about the size of a large drinking straw and some have a balloon on the end to anchor the tube inside the stomach cavity. This procedure takes about 30 minutes although the effects of the sedation can last hours to days. Problems can occur with bleeding and infection; however, the procedure is usually safe. Up to 1/3 of patients may suffer a complication or die within 30 days of the procedure. Older dementia patients have greater risk for complications. The tube is designed to bypass the mouth and food pipe and inject the liquid nourishment directly into the stomach and intestines. This tube allows the patient to receive nutrition without the risk of inhaling food or choking. The tube also eliminates any pleasure associated with eating or drinking.

The use of PEG tubes can help demented patients who have short-term swallowing problems that are expected to improve over time, for example, a patient with a stroke who is improving. These tubes are rarely helpful in end-stage dementia patients who are dying from advanced brain damage.

Studies show that PEG tubes provide little comfort or assistance to end-stage Alzheimer patients. The tube will prevent choking on food because the patient is not longer allowed to eat. The patient will continue to choke on saliva because they have forgotten how to swallow these bacteria-rich liquids. Inhaling saliva causes patients to have pneumonia, termed “aspiration pneumonia”. These repeated chest infections require the patient to receive antibiotics and other

therapy to avoid dying from pneumonia. The use of PEG tubes in persons with advanced dementia does not prolong life expectancy and the patient's nutritional status is not significantly improved. A few individuals may enjoy some relief or comfort from the tube; however, most demented individuals derive little benefit.

The section of the tube outside the abdominal skin must be securely positioned on the abdominal wall to prevent displacing the inner tube. Patients often require binders, i.e., abdominal girdles that cover the tube and prevent them from pulling at the device. When a tube is accidentally removed, the patient may require a second procedure for reinsertion of the feeding device. Patients often pull on the tube because the hole in their outer skin and muscle can become irritated, inflamed or infected. When a tube is only partly displaced, the feedings may get into the abdominal cavity around the stomach producing serious medical complications.

Most end-stage Alzheimer patients who can no longer chew or swallow have less than 6 months of expected life. Invasive procedures like PEG tubes rarely provide significant comfort or symptom improvement. The insertion of a PEG tube removes the need to orally feed or hydrate Alzheimer patients and the patient now loses the human contact provided by the feeding process. The tube is connected to a bag that is attached to a pump and the feeding is infused 2 or 3 times per day. The human contact associated with feeding and drinking is severely reduced because the machine cares for the patient.

The Hospice Alternative

The alternative to feeding machines is hospice care. Hospice services provide active treatment for dying Alzheimer patients. An experienced hospice team that includes doctors, nurses, and other specialists will help the patient and the family through the final stages of living. Hospice staff are trained to manage physical, mental, and spiritual suffering associated with end-of-life care. The hospice team will not withhold food or drink from the dying patient. The team will adjust feedings and hydrations to optimize patient comfort. Eventually, the patients will stop eating and drinking. Advanced-stage Alzheimer patients will drift into a sleep-like state. These individuals rarely experience ongoing starvation or thirst. The hospice team is trained to recognize any discomfort or anxiety and appropriately relieve those symptoms. Hospice staff

will typically coordinate care with family and staff to assure that everyone's human and spiritual needs are met.

Family Responsibility

Caregivers are often overwhelmed by decisions on end-of-life care. Families should never be pressured or rushed into making these crucial decisions. Family should consult with pastors and carefully consider each treatment option. Family members should voice opinions after they learn the facts about dementia and the brain damage produced by these deadly diseases. Hospice treatment is active therapy provided by trained professionals. Families should always consult with a hospice team to determine all possible treatment options for the end-stage patient.

Respecting the Patient

Dementia is a terminal disease. Families are encouraged to discuss end-of-life issues with the demented person while the patient still retains their intellectual ability. Caregiver should honor the directions and requests of persons with dementia who can speak clearly and understand the issues. Extending life is not as important to most older persons as assuring quality, dignity, and comfort.

REFERENCES

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