

# **Physicians Guide to The Role of PEG Tubes in Management of the Terminal Alzheimer Patient**

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Clinicians are often confronted with management decisions for demented patients who no longer retain the ability to maintain adequate weight through oral intake. Swallowing problems are common in nursing home residents and this disability is very common in advanced-stage Alzheimer patients. Most demented patients who develop expressive aphasia also demonstrate problems with silent aspiration. Swallowing dyspraxia and aphasia generally occurs after 5 to 7 years of illness.

## **Weight Loss in Dementia**

The weights of nursing home patients are carefully monitored and nursing home staff becomes concerned about weight loss exceeding survey guidelines (See Table 1). Many assisted living residents or home-bound elders also suffer undetected weight loss. Demented patients with swallowing dyspraxia require large amounts of staff time for feeding and hydration. Families can become alarmed over swallowing difficulty and pressure physicians or nursing staff to “do something for Momma”. Studies on PEG tube usage in patients with end-stage dementia show that families are often encouraged to allow insertion of PEG tubes by medical staff.

Pharmacological intervention can improve oral intake when patients are not swallowing-impaired. Medications like megastrol acetate and dronabinol can increase calorie intake in patients who are able to chew and swallow (See Table 2).

## **The Role of PEG Tubes in Nutritional Management**

PEG tubes may be helpful in patients with mild to moderate dementia who have developed swallowing problems as part of some other temporary problem, e.g., delirium, stroke, etc. PEG tubes may be beneficial in sustaining nutrition while the patient recovers physical vitality and swallowing function. Patients with moderate or severe expressive aphasia are at greater risk for

developing silent aspiration. Coughing or choking during the drinking of 3 oz. of water increase the likelihood of aspiration. Most swallowing dyspraxias occur slowly and abrupt onset of choking suggests a stroke, delirium, or other new neurological problems.

### **Limitations of Effectiveness for PEG Tubes**

Numerous studies and reviews demonstrate that PEG tubes are not effective for end-stage dementia patients. Studies show no substantial improvement in quality of life, life expectancy, or long-term nutritional status. Review articles consistently discourage the use of PEG tubes in dying Alzheimer patients and emphasize the use of hospice services to manage the dying process. Appetite stimulants do not improve feeding in end-stage dementia. Some stimulants may cause delirium (**See Table 2**). PEG tubes can produce serious or life-threatening complications like peritonitis or prolonged restraints (**See Table 3**).

### **Hospice Care for Persons Dying with Dementia**

Families and nursing home staff are often hesitant to use hospice because of misunderstandings about treatment provided through the hospice management system. Families and nursing home staff often misunderstand the active therapy provided by hospice to meet the physical, mental, and spiritual needs of both the dying patient and the family caregivers. Studies show that demented individuals with severe cognitive loss, expressive aphasia, and recurrent infection, i.e., pneumonia, have a life expectancy of 6-months and qualify for hospice care. Physicians are justified in referring the patient and family to hospice when these published criteria are met.

Hospice care provides many services including management of pain, behavioral problems, nutrition, hydration, and family bereavement. The comprehensive management strategies for pain and anxiety continue to be important for persons with dementia. Although cortical damage may reduce a demented person's ability to describe and experience some qualities of pain, discomfort is probably still registered at the thalamic level in demented persons. Pain is often manifested as abnormal behavior, e.g., resistiveness, hostility, and appropriate pain management is essential to any dying patient with Alzheimer's disease. Under-treated pain and depression are common causes of weight loss in demented residents.

## **Complications Associated With PEG Tubes**

Insertion of a PEG tube can produce several unpleasant consequences (Table 3). First, the procedure has inherent risks in debilitated patients and these individuals are at high risk for post-operative delirium. Second, residents who dislodge the tube are often managed with binders or restraints. Third, the loss of feeding and hydration produces further social isolation and lack of human contact as staff must simply “hang another bag”. The family of a PEG tube recipient may not receive the counseling and spiritual support provided by the hospice team. Patients who undergo PEG tube placement continue to suffer from aspiration pneumonia requiring further interventions, e.g., IV antibiotics, IV hydration, hospitalization, etc. Other medical complications such as decubiti, contractures, etc., progress in the patient.

Research shows that families often ignore end-of-life issues until a crisis occur. Family members should be encouraged to discuss these issues with elders while the patient retains the intellectual function to express their self-determination. Family discord is often avoided by thoughtful discussion and careful education of all family participants. Family educational material is available to physicians or caregivers via the website [www.alzbrain.org](http://www.alzbrain.org) or by calling 1-800-457-5679. Families who understand the natural history of dementia and the severity of brain damage produced by the diseases are more likely to express reasonable opinions with regards to resuscitation, heroic measures, and end-of-life care. Most elders choose quality of life and personal dignity over longevity and survival. Self-determination and autonomy is achieved for elders by soliciting their opinions while they are capable of providing informed consent.

## **Dealing with Difficult Family Situations**

Physicians are sometimes placed in difficult positions by families who insist they violate advanced directives that were legally and ethically executed. Physicians are duty-bound to follow advanced directives dictated by the older person. In the situation where a family member demands that the physician disregard a legally executed advanced directive, the unhappy family member can be instructed to immediately hire an attorney and file for an emergency order in the appropriate court so that the judge will instruct the treating physician to disregard the advanced directive. Families can be given this option by the treatment team and those individuals can

choose whether they wish to hire an attorney and seek an immediate court order. Such orders can be achieved within a matter of hours from circuit court, although most judges will inform the petitioner that the treatment team must follow the legally executed wishes of the older individual.

Physicians play a crucial role in end-of-life care. Most families make the right decision for their loved-one when the family members understand the natural history of dementia and limitation of aggressive treatment.

**Table 1**  
**Involuntary Weight Loss Triggers**

<ul style="list-style-type: none"> <li>▪ 5% in 30 days</li> <li>▪ 10% in 180 days</li> <li>▪ BMI <math>\leq</math> 21 or</li> <li>▪ &gt; 25% uneaten food for 2/3 meals over 7 days</li> </ul>
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**Table 2**  
**Effectiveness and Toxicity of Appetite Stimulants in Dementia**

Medication	Dose	Effect	Toxicity
Periactin	N/A	None	Delirium
Megace	800	↑ Weight  ↓ Cytokines	↑ BS  DVT
Dronabinol	2.5 bid	↑ Weight	Mild delirium

**Table 3**  
**Common Complications of PEG Tubes**

Complication	Consequence to Patient
1. Occlusion	Reinsertion
2. Internal Displacement	Peritonitis Reinsertion
3. Removal	Reinsertion Restraints



## **Quick Facts for Clinicians on Peg Tubes in Patients with End-Stage Alzheimer's Disease**

1. PEG tubes rarely prevent aspiration pneumonia.
2. PEG tubes rarely improve long-term nutrition or quality of life
3. Appetite stimulants rarely work in advanced-stage dementia.
4. Some demented patients may remove or dislodge the PEG tube.
5. Most elders desire the best quality of life rather than the longest duration of life.
6. Repeated aspiration pneumonia with advanced dementia predicts six-month survival.
7. Family members do not have the legal authority to verbally change a patient's legal advanced directive.
8. Hospice is the best option for end-stage patients with swallowing dyspraxia.
9. Most families decline PEG tubes when they understand the natural history of dementia.
10. Hospice is active treatment for dying Alzheimer patients and their family caregivers.