Section 22

Feeding Tube CAP

Problem

The Feeding Tube CAP triggers persons with a feeding tube, addressing issues relative to the use of a feeding tube and its potential removal.

The vast majority of feeding tubes in long-term care facilities are percutaneous endoscopic gastrostomy (PEG) tubes — inserted through the stomach wall. Rarely, jejunostomy tubes (J-tubes) are used, which are similar to PEG tubes but are placed beyond the stomach in the gastrointestinal tract, in the jejunum. Both PEG tubes and J-tubes are intended for long-term use (longer than 2 weeks). Nasogastric tubes (NG), which are inserted through a nostril and into the stomach, are intended for short-term acute conditions or as a trial prior to the initiation of long-term feeding (for example, after an acute stroke). These tubes are uncomfortable, may cause nasal and esophageal irritation, and are undignified. Therefore, it is recommended that they not be used for more than 2 weeks. The major focus of this CAP relates to the use of long-term feeding tubes.

There are several causes of eating and swallowing problems among persons in long-term care facilities and those living in the community and receiving home care services. The information presented in this CAP needs to be tailored to the specific clinical considerations in each group and to the broader goals of care of the person (that is, comfort or life prolongation). For example, persons with advanced dementia have an irreversible progressive illness and thus, eating problems need to be considered within the context of end-of-life care. In contrast, dysphagia may be a potentially reversible complication in acute stroke patients, in which case tube-feeding may only be needed temporarily. Persons with Parkinson's disease or other motor neuron diseases may have chronic swallowing problems that require long-term feeding interventions. Finally, head and neck cancers may cause structural complications that result in feeding problems. In all cases, decision making about feeding problems should be shared among practitioners, the person being served, and, when appropriate, family members after considering the particular clinical situation, treatment options, and the person's preferences.

Facts about Tube Feeding

- There is no evidence that the use of a feeding tube improves **survival** in persons with advanced dementia.
- Tube feeding **will not prevent aspiration** of gastric contents or oral secretions. Persons who aspirate prior to the placement of a feeding tube likely will continue to aspirate with the tube.
- The association between the provision of nutrition via feeding tube and the prevention of **pressure ulcers** remains unproven.
- Many family members are concerned that without tube feeding, a terminally ill person will be **hungry or thirsty**. However, it has been shown that persons who are terminally ill do not experience hunger or thirst beyond what can be alleviated with ice chips or glycerin swabs.

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Overall Goals of Care

- Ensure that feeding decisions are in accordance with the overriding goals of care.
- Minimize tube feeding in advanced dementia.
- Ensure the person using a feeding tube receives proper care to manage tube feeding, maintains nutrition, and avoids complications.
- Review periodically the appropriateness of the continued use of tube feeding.
- When not appropriate, consider steps to discontinue tube feeding.

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Feeding Tube CAP Trigger

All persons with a feeding tube will be triggered for review. However, this group is divided according to their cognitive abilities.

TRIGGERED — HAS SOME RESIDUAL COGNITIVE ABILITIES

This subgroup is defined by two factors:

- The person has a feeding tube.
- The person has at least some ability to engage in everyday decision making (a score from Independent to Moderately Impaired).

This subgroup is more likely to be involved in their own decision making about feeding tube use. They will almost always have at least some ability to understand and be understood by others.

This group includes about 3% of persons in long-term care facilities, 1% of persons receiving home care, and almost no older adults living independently in the community.

TRIGGERED — ABSENCE OF COGNITIVE ABILITIES

This subgroup is defined by two factors:

- The person has a feeding tube.
- The person has no ability to engage in everyday decision making (a score of Severely Impaired to No Discernable Consciousness).

This subgroup includes persons who have profound problems. They have little or no ability to communicate with others. Almost all are functionally dependent in all ADLs (they have an ADL Hierarchy score of 6). Eighty percent or more cannot balance themselves in a sitting position, have a swallowing problem, and have no control over their bladder.

This group includes about 3% of persons in long-term care facilities, 1% of persons receiving home care, and almost no older adults living independently in the community.

NOT TRIGGERED — All other persons (those without a feeding tube). The "Not Triggered" group includes about 94% of persons in long-term care facilities, 98% of persons receiving home care, and all, or almost all, persons living independently in the community.

Feeding Tube CAP Guidelines

Involvement of the Health Care Team in the Assessment and Management of Tube-Fed Persons

The use of feeding tubes is a complex issue. The expertise of many disciplines is required to assess and care properly for persons with feeding tubes. Nurses play the primary role and are in the position to identify when the expertise of other team members is needed. Nurses must be prepared to alert the physician and dietician to ongoing care issues, complications, and concerns about the appropriateness of tube feeding. It is recommended that a nutritionist or dietician regularly follow all tube-fed persons to assure appropriate intake corresponds with needs. Other disciplines that may be involved include speech and language pathologists (to assess eating and swallowing capabilities), occupational therapists (for positioning to avoid aspiration), social workers, and clergy (for ethical dilemmas and psychosocial support).

Have psychosocial issues been considered? Eating is an enjoyable social activity, and feeding another person is symbolic of caregiving. Loss of the ability to eat independently can have adverse psychosocial implications for both the person and family members.

- Monitor for signs of depression. [See Mood CAP.]
- Consider other ways to socially engage the person with a feeding tube.
- Provide emotional and social support from social workers, clergy, and other members of the health care team.

Nursing Observations

Provide Ongoing Management of Person with Tube Feed

The DAILY management of a tube-fed person should include the following:

- Clean local area around insertion site.
- Check skin around insertion site for signs of bleeding or local infection (for example, redness, swelling, purulent drainage).
- Monitor for signs or symptoms of gastrointestinal obstruction (abdominal distension, pain, cramping, hard abdomen, loss of bowel sounds, vomiting, high residuals, diarrhea, lack of bowel movements, or fecal impaction).
- Monitor fluid status (dehydration or fluid overload, vomiting).
- Monitor for tube dislodgement.
- Provide nutritional supplements via feeding tube continuously or as boluses several times daily. The choice of nutritional supplement and mode of delivery should be decided by a physician or nutritionist with physician orders.

Periodic evaluations and consultations should include the following:

- Weight checked at least monthly.
- Lab tests performed periodically to monitor electrolytes, serum albumin, and hematocrit.
- Regular periodic evaluations by a nutritionist or dietician.
- Periodic assessment for the possibility of resuming oral feeding. A speech and language pathologist or occupational therapist can help with this assessment.
- Regular changing and replacement of PEG tubes and J-tubes. Individual programs or facilities may differ in their protocol (for example, every 3 months).

Identify and Avoid Complications of Tube-Feeding

Are any of the following direct complications of tube feeding present upon daily evaluation?

Complication	Average % Occurrence	Sign	Actions for Consideration
Infection			
Minor	4	Cellulitis around tube insertion	Local antibiotic ointment
Major	1	Fever, hypotension, diaphoresis (sweating)	Consult physician
Bleeding			
Minor	< 1	Bleeding around insertion	Consult physician
Major	almost 0	Hypotension, drop in Hematocrit, frank blood	Medical emergency; stabilize person and consult physician
Diarrhea and cramping	12	Pain, diarrhea, dehydration	Examine abdomen for signs of obstruction* Consult physician Rule out GI infection Consult nutritionist (may need to change supplement)
Nausea and vomiting	9	Nausea, vomiting, abdominal distention, dehydration	Check for residuals,* slow feeds,* examine abdomen for signs of obstruction,* avoid aspiration Consult physician and nutritionist
Minor tube problem	4		All may require physician consultation
Dislodgement		Tube no longer in place	Replace tube (Foley catheter sometimes used)
Blockage		Disrupted flow of supplement	Flush tube with water or ginger ale

Leakage		Leaking around tube	Tube may need replacing (Foley catheter sometimes used)
Major tube problem (Bowel perforation)	< 1	Absent bowel sounds, tense abdomen, nausea, vomiting, diarrhea, or absent bowel movements (fecal impaction), hypotension	Medical emergency Consult physician immediately

***Definitions:**
Signs of obstruction: Include abdominal cramps, vomiting, abdominal distention, absent or high-pitched bowel sounds, abdominal tenderness.
Residuals: The amount of food remaining in the stomach upon gastric aspiration prior to giving a feeding.
Slow feeding: Feeding that progresses slower than the prescribed drip rate.

Are any of the following other serious complications related to the use of feeding tubes present?

- **Aspiration —** Tube feeding will not prevent a person from aspirating. Persons who were aspirating prior to the feeding tube insertion remain at high risk of recurrent aspiration of oral secretions and gastric contents. Silent aspiration occurs often. Aspiration is uncomfortable for the person and can lead to aspiration pneumonia.
- **Strategies to prevent aspiration in a tube-fed person include the following:**
  - Choose appropriate rate for tube feeding (consult with physician and nutritionist/dietician)
  - Monitor for high residuals
  - Oral suctioning when appropriate
  - If taking food orally, use proper feeding techniques. Consult nutritionist, occupational therapist, or speech and language pathologist, as necessary
- **Signs and symptoms of aspiration pneumonia:**
  - Coughing, shortness of breath, increased sputum production
  - Fever, increased respiratory rate, diaphoresis, decline in mental status, agitation
  - Hypotension, signs of dehydration
- **Laboratory results:**
  - Elevated white blood cell count, elevated blood urea nitrogen, creatinine, or sodium
  - Consolidation on chest x-ray
  - Hypoxia
- **Actions for consideration:**
  - Stabilize person (for example, consider the use of oxygen)
  - Consult physician, respiratory therapist
  - Person may need antibiotics and parenteral IV hydration

Is the person physically restrained or receiving psychotropic medication? Persons who are tube fed often have cognitive problems and are easily agitated. They may try to pull out the feeding tube. Thus, agitated persons with feeding tubes are at high risk of being restrained or given psychotropic medications for sedation. Studies have shown that persons who live in long-term care facilities who are tube fed are more likely to be restrained compared to those who are not tube fed. **Both physical restraints and psychotropic medications can have serious adverse consequences and should be avoided and used only as a last resort to maintain the tube.** [See CAPs on Physical Restraints and Appropriate Medications.]

Periodically assess the appropriateness of ongoing tube feeding. The decision to insert a feeding tube was made at some prior time. [See CAPs for Undernutrition and Dehydration.] As with all medical therapies, its continued use should be reassessed periodically to ensure that it continues to meet the goals of care for this person. Technically, it is very easy to stop tube feeding (most PEG tubes are designed to be removed with moderate traction safely and painlessly). However, emotionally and ethically, discontinuation of tube feeding can be very difficult, and any psychosocial needs of the person and family should be supported.

Reasons to discontinue tube feeding include the following:

- The person has improved enough to eat and drink by mouth. Consider involving a nutritionist, speech and language pathologist, or occupational therapist in this assessment.
- The person has not improved in overall status or adequate oral intake and tube feeding no longer meets the goals of care. Alternative management strategies to consider include
  - A conscientious approach to hand-feeding. While hand-feeding may not provide caloric intake, it may provide some positive quality of life for the person.
  - Supportive care (for example, pain control, treatment for shortness of breath, use of glycerin swabs or ice chips to keep the mouth moist, skin care, psychosocial support, etc.) in a terminally ill person.

Steps to Consider in Discontinuation of Tube Feeding in Persons Who Have Not Improved in Swallowing or Adequate Oral Intake

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Laws must be taken into account with regard to the discontinuation of tube feeding and may differ from jurisdiction to jurisdiction.

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Is the person cognitively intact and capable of making his or her own health care decisions?

- Consider meeting with involved members of the health care team to establish the person's status with regard to tube feeding.
- Consider designating members of the health care team, including the physician, to approach the person to review his or her status, the risks and benefits of tube feeding versus supportive care or hand feeding, and to elicit the person's preference for tube feeding. This must be an **informed** decision.

- Involve a family member(s) in the decision-making process as appropriate.
- Respect the person's choice.

Is the person cognitively impaired and incapable of making his or her own health care decisions?

- Consider meeting with involved members of the health care team to establish the person's status with regard to tube feeding.
- Identify the person who has been either formally or informally designated the substitute decision maker for the person (health care proxy).
- Consider a meeting with the designated members of the health care team, including the physician and the substitute decision maker, to review the person's status, the risks and benefits of tube feeding versus supportive care, and to provide counseling regarding the continuation of tube feeding.

If the person is cognitively impaired and incapable of making his or her own health care decisions, has a substitute decision maker been counseled to consider the following?

- Does the person have a written advance directive indicating whether or not he or she would want to be tube fed in the current situation?
- Has the person ever verbally communicated with family members or health practitioners if he or she would want to be tube fed under the current circumstances?
- After considering what is known about the person's values and preferences, does the substitute decision maker feel the person would want to continue tube feeding in the current situation if the person were capable of making a decision (a substituted judgment)?
- After being informed of the risks and benefits of tube feeding, is it in the person's best interests to continue tube feeding?

Is there conflict between the person's advance directive or best interests and the substitute decision maker's choice?

- In most instances, when the substitute decision maker's choice is fully informed, the choice of the substitute decision maker and the wishes of the person as expressed in the advance directive are the same. In this situation the choice of the substitute decision maker should be respected.
- Rarely, the substitute decision maker's choice may appear to contradict a person's advance directive or best interests. All attempts should be made by the health care team to reach an informed decision with the substitute decision maker. In extraordinary circumstances, referral to an ethics committee or a court may be indicated.

Additional Resources

Finucane TE, Christmas C, Travis K. 1999. Tube feeding in patients with advanced dementia: A review of the evidence. *JAMA* 282: 1365–70. **Note:** This

article reviews the current evidence of the impact of tube feeding in patients with advanced dementia.

Gillick MR. 2000. Rethinking the role of tube feeding in patients with advanced dementia. *NEJM* 342: 206–10. **Note:** This thoughtful piece presents the controversies related to tube feeding in advanced dementia.

Mitchell SL, Tetroe A, O'Connor AM. 2000. Making choices: Long-term feeding tube placement in elderly patients. **Note:** This is a booklet and audiotape designed to assist substitute decision makers with the dilemma of whether to place a feeding tube on an older person with eating problems. It contains information regarding tube feeding, including its risks and benefits, substitute decision making, and how to weigh the information together with the patients' values and preferences. The decision aid can be viewed and ordered online at www.lri.ca/programs/ceu/ohdec/decision_aids.htm or by calling the toll free number (U.S. and Canada only) 888-240-7002.

Schneider SM, Raina C, Pugliese P, Pouget I, Rampal P, Hebuterne X. 2001. Outcome of patients treated with home enteral nutrition. *JPEN J Parenter Enteral Nutr.* (July–August) 25(4): 203–9. **Note:** This article is evidence-based and gives additional values to the topics.

Sheehan MN, Belleville-Taylor P, Fiatarone M, Hartery S. 1997. Feeding tubes. In Morris JN, Lipsitz LA, Murphy KM, Belleville-Taylor P, eds. *Quality care in the nursing home.* St. Louis, MO: Mosby. **Note:** This chapter provides a detailed overview of assessment and management of the person with a feeding tube. Case examples are presented.

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