WebEx Quick Reference

- Welcome to today’s session!
- Please use Chat to “All Participants” for questions
- For technology issues only, please Chat to “Host”
- WebEx Technical Support: 866-569-3239
- Dial-in Info: Communicate / Join Teleconference (in menu)

When Chatting…

Please send your message to All Participants …NOT All Attendees
Overall Program Aim

The aim of this Expedition, Managing Advanced Disease and Palliative Care, is to help health professionals empower patients and families to make more informed choices about the use of specific life-sustaining treatments when coping with a serious illness.

Objectives of Expedition

- **Describe** the positive outcomes for all parties — patients with advanced illness, their families, health care providers, and institutions — that arise from outstanding informed consent, education, and advance care planning
- **Assess** their current system for conducting and documenting the informed consent conversation process at critical junctures in advanced illness: initiating tube feeding, kidney dialysis, or antibiotics
- **Identify** process steps and test improvements in the informed consent, documentation, and education processes for patients and families
- **Develop** a quality monitoring process for ongoing assessment of compliance with informed consent standards

Introducing faculty

Carol Monteleoni, MS, CCC-SLP, is a speech-language pathologist in private practice in Olivebridge, New York. During her tenure as Coordinator of Speech-Language Pathology at Lenox Hill Hospital in New York City, she led a multidisciplinary team in conducting a rapid cycle quality improvement project which substantially reduced feeding tube placements in patients with advanced dementia. A certified Educating Physicians in End of Life Care trainer, she has produced articles and presentations for speech pathologists and other medical professionals in the US and Europe, on feeding issues at the end of life.
Assignment Review

- Was there documentation of diagnosis of dementia and stage of dementia?
- Who suggested PEG?
- Was a reason given for suggested PEG placement?
- Who obtained consent?
- Who provided consent?
- Was there documentation of an advance directive re ANH?
- Was there documentation of a HCP?
- Was there documentation of discussion of prognosis with/without PEG?
- Was there documentation patient’s goals of care?
- Did the patient die on same admission?

Common Scenario

- 75 y/o man with moderate to severe dementia.
- Admission for second episode of aspiration pneumonia in 2 months.
- Non-ambulatory; minimal speech
- Wet-gurgly voice, coughs while eating

Questions?

- What is the data that feeding tubes in this population ...
  - Prolong survival
  - Improve quality of life
  - Reduce other complications of dementia
- What alternatives exist?
- How should the discussion be conducted?
Feeding Tubes

- The suggestion that a feeding tube might be a therapeutic option is an opportunity for shared-decision making and goal setting.
- Goals can only be truly made in the setting of true informed consent.
  - Description of the procedure
  - Risks/benefits
  - Alternatives
  - A recommendation

Cultural Considerations

- Equation of food with nurturing, caring
- Beliefs regarding what constitutes meaningful life
- Religious traditions and policies regarding end of life care
- Degree of familiarity with "culture of medicine"

Feeding tube prevalence

- Feeding tubes placed annually in U.S. inpatients 65 and older:
  
<table>
<thead>
<tr>
<th>Year</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1989</td>
<td>~ 15,000</td>
</tr>
<tr>
<td>1995</td>
<td>~123,000</td>
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</tbody>
</table>
  
- Feeding tube insertion rate in nursing home patients with advanced cognitive impairment in US hospitals:
  
<table>
<thead>
<tr>
<th>Year</th>
<th>Rate</th>
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<tbody>
<tr>
<td>2000</td>
<td>7.9%</td>
</tr>
<tr>
<td>2007</td>
<td>6.2%</td>
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</tbody>
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Sources:

Concerns with increased PEG use

<table>
<thead>
<tr>
<th></th>
<th>1992</th>
<th>2002</th>
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<tbody>
<tr>
<td>Procedure related</td>
<td>2%</td>
<td>0%</td>
</tr>
<tr>
<td>mortality</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30-day mortality</td>
<td>8%</td>
<td>22%</td>
</tr>
<tr>
<td>Non evidence-based</td>
<td>16%</td>
<td>31%</td>
</tr>
<tr>
<td>indications</td>
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</tbody>
</table>


PEG effectiveness

NO evidence that tube-feeding in patients with advanced dementia:

- Prolongs survival
- Prevents aspiration pneumonia
- Reduces the risk of pressure sores or infections
- Improves function
- Provides comfort


Poor Prognostic Indicators for PEG Placement

- Age > 75
- Male gender
- Diabetes mellitus
- COPD
- Advanced cancer
- Previous aspiration
- UTI
- Charlson score > 3
- Low BMI
- Albumin < 3 g/dl
- Hospitalized
- Bedridden
- Pressure sores
- Dementia


### Burdens and complications associated with PEG tube use (partial list)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wound dehiscence</td>
<td>Local bleeding</td>
</tr>
<tr>
<td>Skin excoriation</td>
<td>Hematoma</td>
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<tr>
<td>Tube migration</td>
<td>Tube malfunction</td>
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<tr>
<td>Pain at tube site</td>
<td>Aspiration</td>
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<tr>
<td>Gastric prolapse</td>
<td>Gastroic fistula</td>
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<tr>
<td>Evisceration</td>
<td>Pneumatisis intestinalis</td>
</tr>
<tr>
<td>Intussusception</td>
<td>Pneumoperitoneum</td>
</tr>
<tr>
<td>Necrotizing fascitis</td>
<td>Abdominal abscess</td>
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<tr>
<td>Diarrhea</td>
<td>Bowel obstruction</td>
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<tr>
<td>Nausea</td>
<td>Gastroesophageal reflux</td>
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<tr>
<td>Fluid overload</td>
<td>Death</td>
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<tr>
<td>Metabolic disturbance</td>
<td>Loss of gustatory pleasure</td>
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<tr>
<td>Esophageal perforation</td>
<td>Pneumonia</td>
</tr>
</tbody>
</table>


### Benefits and Burdens of PEG Placement

Adapted from Rochester Community-wide Clinical Guidelines Initiative

<table>
<thead>
<tr>
<th>Condition</th>
<th>Likely</th>
<th>Short term</th>
<th>Not Likely</th>
<th>Likely</th>
<th>Short term</th>
<th>Not Likely</th>
<th>Likely</th>
<th>Short term</th>
<th>Not Likely</th>
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<tbody>
<tr>
<td>Dysphagic Stroke</td>
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<tr>
<td>Stroke</td>
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<tr>
<td>(patients with previous good quality of life, high functional status and minimal co-morbidities)</td>
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<tr>
<td>(patients with decreased level of consciousness, multiple co-morbidities, poor functional status prior to CVA)</td>
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<tr>
<td>Amyotrophic Lateral Sclerosis (ALS)</td>
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<tr>
<td>Persistent Vegetative State (PVS)</td>
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<tr>
<td>General Frailty (patients with multiple co-morbidities, poor functional status, failure to thrive)</td>
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<td>Advanced Dementia (patients needing help with daily care, having trouble communicating, incontinent)</td>
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<tr>
<td>Advanced Cancer (excludes patients with early stage esophageal and oral cancer)</td>
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<tr>
<td>Advanced Organ Failure (Patients with CHF, renal or liver failure, COPD, anorexia-cachexia syndrome)</td>
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</tbody>
</table>

### Summary

- Feeding Tubes have limited to no role in patients with chronic, progressive, life limiting diseases, in which there is moderate to severe irreversible cognitive impairment.
  - The inability to maintain oral nutrition in these patients is a marker of the dying process.
Questions?

If no tube, then what?

- Recognize treatable problems leading to feeding difficulty (appendix slides)
- Seek speech pathology consultation
- Establish patient-centered goals of care
- Discuss methods/benefits/risks of oral feeding compared to tube feeding
- Make a recommendation based on your clinical experience/knowledge/judgment

Discussing options

- Shared recognition and understanding of natural disease process and prognosis
- Consensus on goals of care
- Respect for patient’s advance directives
- Respect for family members as part of the unit of care
- Primacy of patient’s welfare vs. institutional pressures
- Appropriateness and availability of hospice services
Changing the System of Care

- Standards of care
- Policies: assessment/communication
- Standard forms/templates
- Patient/Family education
- Health Professional education
- Quality improvement initiatives

Questions?

Quality improvement project to reduce PEGs in patients with advanced dementia

- Multidisciplinary team
- Before/after format
- Aims to accomplish within 9 months
  - 50% reduction PEG placement in demented patients
  - No PEGs in patients who can eat or who have an advance directive not to use Artificial Nutrition
- Interventions: education and PC consult service
Learning from experience

Needs identified
- End-of-life education for physicians, nurses, allied health professionals
- Advanced directives
- Goals of care
- Intra-team communication
- Carry-over of goals between hospital and LTC
- Formal capacity determinations

Proposed policy changes
- PC consult before PEG insertion
- Waiting period before PEG insertion
- EPEC curriculum for house staff
- Hospice alliances, education for discharge planners re: hospice
- Required goals of care discussions in ICU

Measurable outcomes

PEG PROJECT DATA
Most important contributors to success

- Multidisciplinary team including highly motivated speech pathologist
- Support from top hospital administration
- Wide net of outreach throughout the hospital

Your Turn

- Right now…
  - Determine a project Aim; for example:
    - Reduce the number of feeding tubes placed in patients with dementia by 20% over the next 6 months

- Write your Aim in the Chat Box

Your Turn

- Determine a unit to pilot a systems-change project that you think would be open to a new approach; for example inpatient neurology

- Write your answer in the chat box
Your Turn

—Determine ONE intervention that you’d like to institute in the next few months: for example:
- Standard template for feeding tube decision analysis/documentation of informed consent
- Policy development re: required steps of feeding tube decision process: who to involve, what education material to provide, etc.
- Utilize standard Patient/Family education material
- Communication training for selected clinicians involved in feeding tube decisions

—Write in Chat Box

Your Turn

- Make a list of 3-6 key individuals (by name) to bring together as a feeding tube workgroup, for example:
  - Palliative Care
  - Speech/Language Pathology
  - GI and Interventional radiology
  - Quality improvement
  - Neuro ICU

- Keep the list, don’t put in the Chat Box

Barriers

- Name the biggest barrier you anticipate to accomplishing your Aim

- Write in the chat box
Homework

- In the next two weeks...
  - Contact individuals you identified in the prior slide
  - Arrange a meeting date, ideally before the next session (June 9)
    - Share information learned in this project; If not in person, then via e-mail
  - Invite them to join you two weeks from now
  - Think more about what you’d like to accomplish re: feeding tubes

Next Session

- Review what you have done
- Continue planning for improving discussions and decision making for feeding tubes
- Prep for Session 6: Antibiotics

References

Appendices: Contributors to Feeding Problems

Table 1: Potential Contributors to Feeding Problems

<table>
<thead>
<tr>
<th>Condition</th>
<th>Contributing Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia, depression or anxiety</td>
<td>Depression, medication side effects, hypothyroidism, medication requirement, decline in social support</td>
</tr>
<tr>
<td>Poor oral hygiene and dentition</td>
<td>Oral pain, neglect</td>
</tr>
<tr>
<td>Head and neck cancer</td>
<td>Head and neck cancer, medications, radiation, weight loss</td>
</tr>
<tr>
<td>Dysphagia</td>
<td>Dysphagia, aspiration, medications, radiation therapy</td>
</tr>
<tr>
<td>Neurodegeneration</td>
<td>Neurodegeneration, cerebral atrophy, cerebrovascular disease, dementia</td>
</tr>
<tr>
<td>Cerebral atrophy or cerebrovascular disease</td>
<td>Cerebral atrophy, cerebrovascular disease, dementia</td>
</tr>
<tr>
<td>Dentures</td>
<td>Dentures, pain, discomfort</td>
</tr>
<tr>
<td>Dental issues</td>
<td>Dental issues, pain, discomfort</td>
</tr>
<tr>
<td>Head and neck cancer</td>
<td>Head and neck cancer, radiation therapy, weight loss</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>Depression, lack of appetite, nausea, vomiting, weight loss</td>
</tr>
</tbody>
</table>


Feeding management strategies

Table 2: Common Eating Problems in Dementia and Their Management Strategies

<table>
<thead>
<tr>
<th>Problem</th>
<th>Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient resists eating or being fed in hospital</td>
<td>Experience with feeding, use of feeding devices, modification of environment</td>
</tr>
<tr>
<td>Patient refuses to eat</td>
<td>Experience with feeding, use of feeding devices, modification of environment</td>
</tr>
<tr>
<td>Patient has difficulty chewing or swallowing</td>
<td>Experience with feeding, use of feeding devices, modification of environment</td>
</tr>
<tr>
<td>Patient lacks appetite</td>
<td>Experience with feeding, use of feeding devices, modification of environment</td>
</tr>
<tr>
<td>Patient has poor oral hygiene</td>
<td>Experience with feeding, use of feeding devices, modification of environment</td>
</tr>
</tbody>
</table>


Improving the System of Care

Table 3: Strategies for Improvement of Care for Individuals with Dementia

<table>
<thead>
<tr>
<th>Target Area</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bedtime routine</td>
<td>Bedtime routine, sleep hygiene, support, increased social interaction, reduced stimulation, medication management</td>
</tr>
<tr>
<td>Professional education</td>
<td>Professional education, ongoing education, support, increased social interaction, reduced stimulation, medication management</td>
</tr>
<tr>
<td>Institutional policies and procedures</td>
<td>Institutional policies, procedures, support, increased social interaction, reduced stimulation, medication management</td>
</tr>
<tr>
<td>Interventions</td>
<td>Interventions, support, increased social interaction, reduced stimulation, medication management</td>
</tr>
<tr>
<td>Personalized care</td>
<td>Personalized care, support, increased social interaction, reduced stimulation, medication management</td>
</tr>
</tbody>
</table>