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)

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

This Expedition

- Certain medical interventions provide critical junctures that allow us to pause and connect with patients and their families about what the goals of care. These conversations can prevent us from being in the position of providing care that is excessive in relation to their wishes or their course of illness.
- A central tenet of palliative care is to match the right procedure for the right patient at the right time.
Introducing faculty

Carol Monteleoni, MS, CCC-SLP
• Speech-language pathologist in private practice in Olivebridge, NY
• During tenure as Coordinator of Speech-Language Pathology at Lenox Hill Hospital, led a multidisciplinary team in conducting a rapid cycle quality improvement project which substantially reduced feeding tube placements in patients with advanced dementia

David E. Weissman, MD
• Professor Emeritus, Palliative Care Program, Medical College of Wisconsin
• Consultant, Center to Advance Palliative Care

Today’s Focus…

• Hearing what teams have been testing to improve informed consent conversations about feeding tubes
• Shared learning
• Opportunity to ask questions
• Preparation for session 6 regarding informed consent conversations about antibiotics for patients with advanced illness

Review: Goal setting

• 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
Benefits and Burdens of PEG Placement
Adapted from Rochester Community-wide Clinical Guidelines Initiative

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

Conclusions from Session 4

• 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

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
Measurable outcomes

PEG PROJECT DATA


Resources

- Rochester Community Guidelines
  - Flowchart for patient unable to maintain intake
  - Benefits/Burdens Table
  - Patient/Family Education Page
  - Feeding tube assessment worksheet
  - Tube feeding worksheet

- Froedtert Hospital Palliative Care Program
  - Patient/Family Education booklet
- Handbook for Mortals (J Lynn)
- Mitchell SL, Tetroe JM, O'Connor AM. Making Choices: Long Term Feeding Tube Placement in Elderly Patients, a booklet and audio tape for surrogate decision makers. Ottawa,
  [http://decisionaid.ohri.ca/decoids.html#feedingtube](http://decisionaid.ohri.ca/decoids.html#feedingtube)
Last Session

- One Aim
- Location to start
- Workgroup members
- Barriers
- Convene workgroup and share information prior to today's call

Your turn

- What have you tried/tested since our last session?
- Were you able to convene a workgroup?
- What questions do you have?

Homework

- Review 10 recent charts of hospitalized patients with dementia and aspiration pneumonia, admitted through the ED
- Examine the documentation for discussion of:
  - Discussion with surrogate if pt is non-decisional
  - Review of AD if available
  - Patient/surrogate defined Goal of Care (life prolongation vs. comfort)
  - Purpose/rationale of using Abs
  - Risks and Benefits
  - Prognosis w/ and w/o Abs
  - Alternatives including no Abs
  - Clinician Recommendation
Next Sessions

Session #6: June 23rd 1-2pm ET
• Dr. Tammie Quest will be our guest speaker re: antibiotics

Then:
Session #7: July 7th 1-2pm ET
• Teams report out about testing for antibiotics informed consent processes