Didactic

“Artificial Nutrition in the Setting of Advanced Dementia”

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Artificial Nutrition in the Setting of Advanced Dementia

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Learning Objectives

In case-based interactive discussion you will be able to:

- Identify the questions and concerns of families and clinicians surrounding the use of AN in patients with advanced dementia.
- Formulate two possible medical recommendations that match family preferences.
- Review literature on artificial nutrition in advanced dementia

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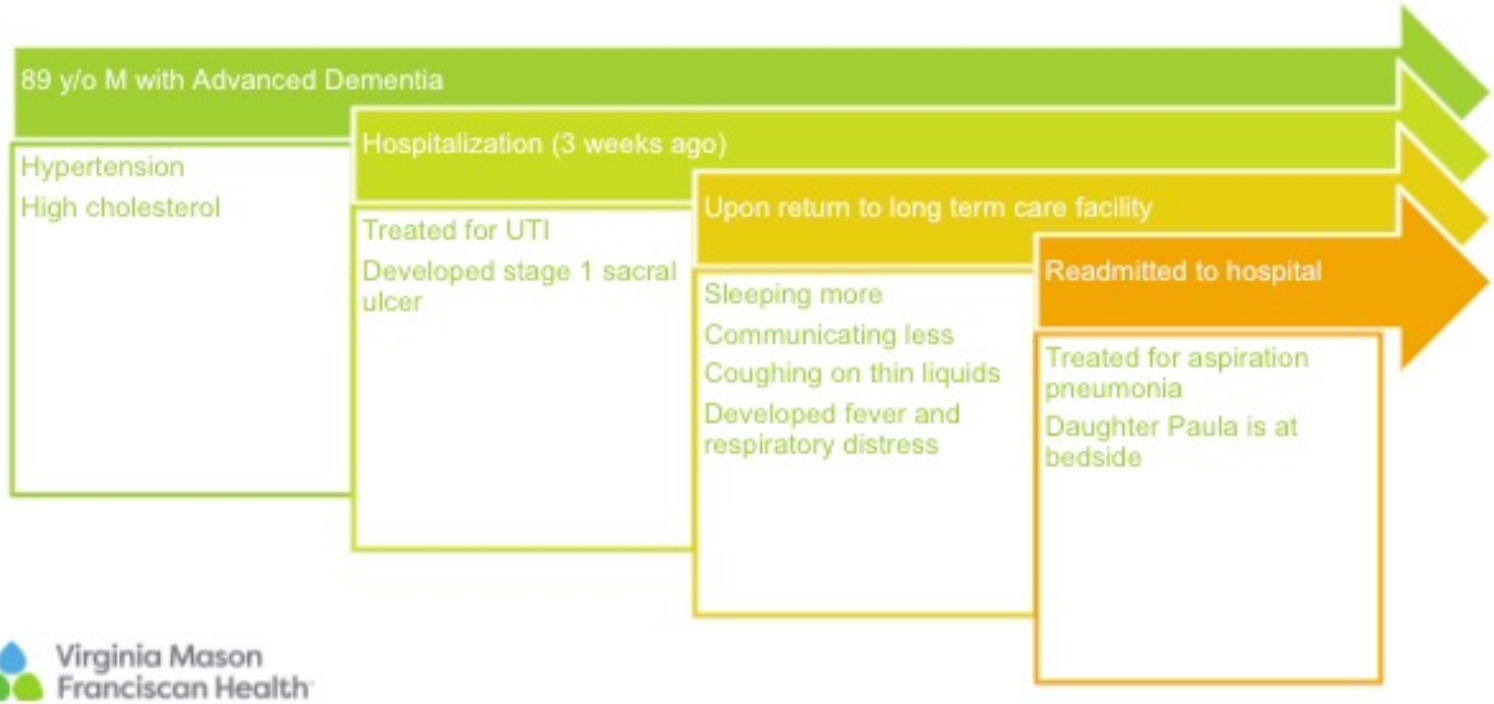
The patient: Mr. B.



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“Big picture” considerations:

What is happening to Mr. B?

- He has advanced dementia

Would you be surprised if he were to die within the next 6 months?

- He is at risk for dying within weeks to months.

What is Paula likely to be feeling? Is this conversation likely to be a high-intensity or low-intensity emotionally?

- High. Potential for feeling grief, fear, or perhaps even shame.

What do we know about artificial nutrition in this setting?

Review of Literature

American Academy of Hospice and Palliative Medicine

Released February 21, 2013; Revised January 14, 2021

Don't recommend percutaneous feeding tubes in patients with advanced dementia; instead, offer oral assisted feeding.

In advanced dementia, studies have found feeding tubes do not result in improved survival, prevention of aspiration pneumonia, or improved healing of pressure ulcers. Feeding tube use in such patients has actually been associated with pressure ulcer development, use of physical and pharmacological restraints, and patient distress about the tube itself. Assistance with oral feeding is an evidence-based approach to provide nutrition for patients with advanced dementia and feeding problems; in the final phase of this disease, assisted feeding may focus on comfort and human interaction more than nutritional goals.

https://www.choosingwisely.org/clinician-lists/american-academy-hospice-palliative-care-percutaneous-feeding-tubes-in-patients-with-dementia/

Following the patient/families cues…

EMOTIONAL vs. COGNITIVE

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Advanced communication skills-

Do not use the phrase “I understand…”

- 50% of clinician’s believed stating “I understand” conveys empathy, ***75% of patients*** in prior studies ***perceive “I understand” statements from clinicians as dismissive and disrespectful***

  -“Clinician’s views on empathy is a barrier” - Comer, A et al. Indiana University JPSM June 2020)

Use empathic statements....

- “I can’t imagine how difficult this must be”
- “I wish I could make this into better news”

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Emotional Cue or Cognitive Cue?

- **"There must be something you can do."**
  - **Respond to emotion**: "I wish that I could make this into good news."

- **"I want a second opinion."**
  - **Respond to emotion**: "I can't imagine how difficult this must be."

- **"We're hoping for a miracle."**
  - **Respond to emotion**: "That would be awesome. If it happens, we will celebrate that miracle with you. And… is it OK if we also talk about how we will care for mom if what we're hoping for doesn't happen?" **aligning hope / intention**

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It is crucial to leave spiritual sources of strength and hope intact.

What are the possible options for ongoing care?

Options to consider:

- Artificial feeding via PEG tube - does not positively impact weight nor pressure ulcers, may increase morbidity, does not improve survival vs those who are carefully hand fed
- Time-limited trial of tube feedings via Dobhoff / Keofeed with specific goals
- Comfort feedings: 1:1 hand feeding (every 4 hours while awake), managing symptoms, engaging Hospice and allowing natural death.
- What about TPN?
  - No. TPN is meant as a short-term intervention to foster recovery after surgery, chemotherapy, radiation etc.

Family concerns vs clinician concerns regarding AN in Advanced Dementia

What concerns families?

What concerns clinicians?

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Why do we eat?

Write top 2 reasons you eat in chat box.

FOOD = LOVE

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Of the possible options for Mr. B, which is the best match for the reasons most of us eat?

A) Artificial feeding via PEG tube

B) Time-limited trial of tube feedings via Dobhoff / Keofeed with specific goals

C) Comfort feedings: 1:1 hand feeding (every 4 hours while awake), managing symptoms, engaging Hospice and allowing natural death.

Relationship	• Quiet space, silence phones and pager, request permission to enter, sit down, eye contact • Assess symptoms first • Elicit their agenda first • Review medical records, talk to rest of the team	• *Ask permission* "Is this a good time to talk?" • Are you comfortable enough to talk now? • What are your expectations for our conversation today? • We want to provide you the **Best Care Possible** *from your perspective*. Can we talk about that?
Patient Story	• Match the pace of the patient • Listen carefully • Don't interrupt • Anticipate emotions	*Obtain Patient Story:* "Can you tell me, *in your own words*, what you have heard about your medical condition? Are you able to do the things you enjoy? Where do you get strength and support? What is your body telling you?
Medical Story	• If they do not want to talk, don't proceed • Offer only realistic hope • Deliver information in "Headlines" (25 words or less) • Avoid medical jargon	• *Ask permission:* Would it be okay if I share medical information now? • **Deliver Headline & BE SILENT (let them break silence!)** "I am worried that what we are hoping for may not happen" "The cancer has come back" • *Name Emotion/Empathetic Statement/Align Hope* "This is hard" "I cannot imagine" "I wish I could make this into good news, but I can't" "This is upsetting" ***Align hope/intention:*** *My hope is that you/your loved one will get better. I also want us to have a plan if what we are hoping for doesn't happen.* "Given your medical situation, what is most important to you?"
Recommendation	• Make a medical recommendation that aligns patient priorities **AND** reflects what is medically possible • When you recommend limiting interventions, make sure you first offer what you WILL do	*Before Making a Recommendation:* • This is what I hear is important to you. (list them) • Is this correct? (confirm that the list is correct) • Would it be okay if I make a recommendation? **(ASK PERMISSION)** *When making a recommendation:* "Based on what is important to you, I recommend the following" Make recommendations that match their goals. *After making a recommendation:* What do you think about this as a plan? (Obtain their opinion about your recommendations)
Collaborative	• Continue to partner with them • Consider a time limited trial w/specific goal • Protect the quality of the process rather than judging the quality of their decision	• *Affirm their decision:* Let me summarize what I have heard from you: "It sounds like it is really important to you that we place a PEG/Trach with Abx/ intubate / perform CPR" • **Establish a Functional End-Point for Time-Trial** **Going forward, how will we know that this plan is working/not working?** (e.g. patient: "more awake/participate in PT/come off Respirator") • **Finish with Teach-Back**: "To make sure I have done a good job communicating, can you share with me what we talked about?

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Advanced communication skills-

Support decisional surrogates...

- A 2011 review of 40 studies looked at over 2,000 surrogate decision makers, most of whom were involved in medical decision making at end of life. **33% of those surrogates reported lasting psychological trauma associated with their experience!**
- Just giving "the facts" isn't enough- a web based decision aid for surrogates of critically ill ventilated patient resulted in 43% choosing a more aggressive treatment plan than what they identified as the patient's treatment preference - **Dionne-Odom, PHD, RN and White, MD, MAS 'Reconceptualizing How to support Surrogates Making Medical Decision for Critically Ill Patients. JAMA, June 1, 2021 Vol 325 No 21**

Elicit substituted judgement....

- "If mom were sitting in this empty chair, what would she tell us to do?"
- "If dad was aware of his current medical condition, how would he want us to care for him?"

The patient's story

Will each of you please type one question you would like to ask Paula in the chat box?

Let's practice using the house model starting with relationship building and obtaining the patient's story…….

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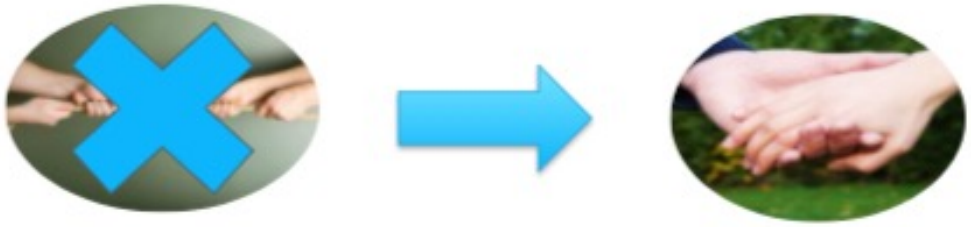
What if Paula doesn't accept your recommendation?



- Go up to the roof of the house: **collaborative decision making**
  - Affirm their decision
    - Offer a **time-limited trial**
      - Establish a specific endpoint

.....Finish with **Teach-back**

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Facilitating collaborative decision making

Paula: “I just feel like I’m not ready to give up on the possibility that dad might get better if we feed him. I think we should try the tube feedings.”

Clinician: “It sounds like it’s really important to you that we try tube feedings with your dad.” (affirming decision) **“I’d like to suggest a time limited trial of feedings through a temporary tube x 1 week.”** (timed trial) “**If it is helping we would expect to see your dad being more alert and engaged with caregivers. We may consider stopping the trial early if your dad develops additional symptom burden such as agitation or shortness of breath.”** (specific end point) **“So that I know I’ve done a good job communicating, can you tell me in your own words what we’ve talked about?”** (teach back)

Thank You!!

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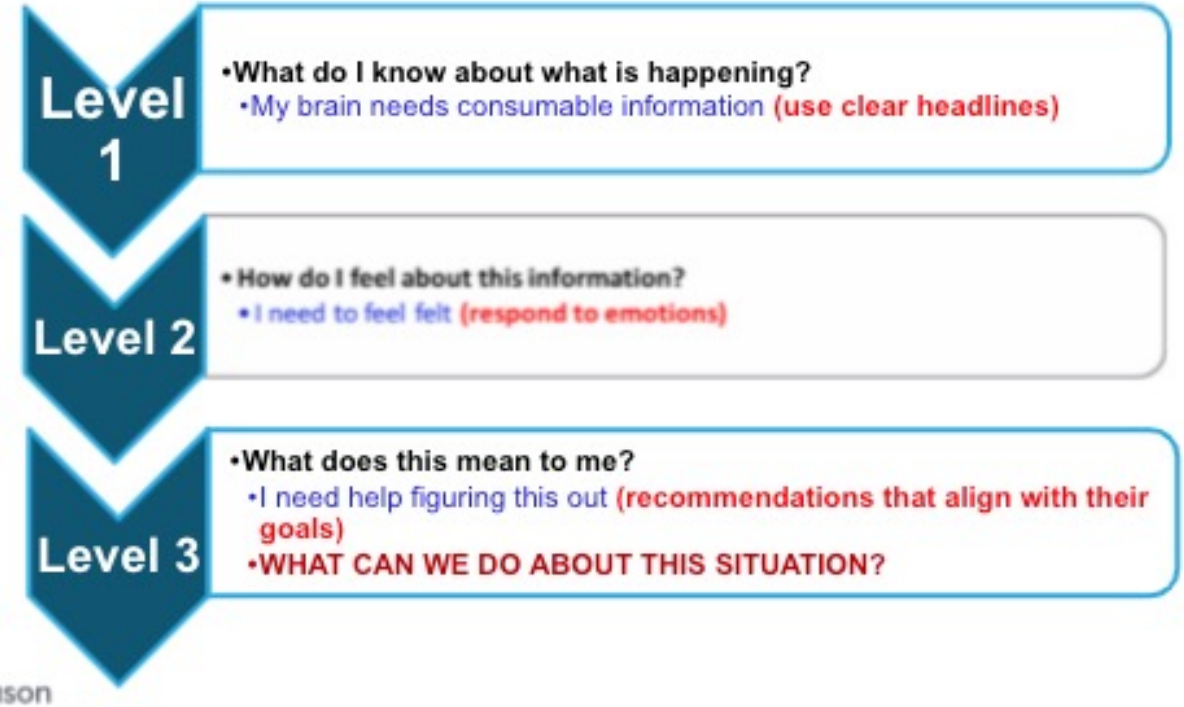
Identifying the Three Levels/Components of every conversation

Harvard Negotiation Project @ Harvard Business School 2012 (Difficult Conversations Publication)
Anthony Back et al. Approaching Difficult Communication Tasks in Oncology. CA A Cancer Journal for Clinicians 2005;55:164-167



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