Feeding in the Setting of Advanced Dementia

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Learning Objectives

- Identify the questions and concerns of families surrounding the use of ANH in patients with advanced dementia.
- Identify the concerns of clinicians surrounding the use of ANH in patients with advanced dementia.
- Formulate two possible medical recommendations that match family preferences for the case presented.
- Recognize and respond to emotional cues in conversations about high consequence decisions

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Reflection

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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.

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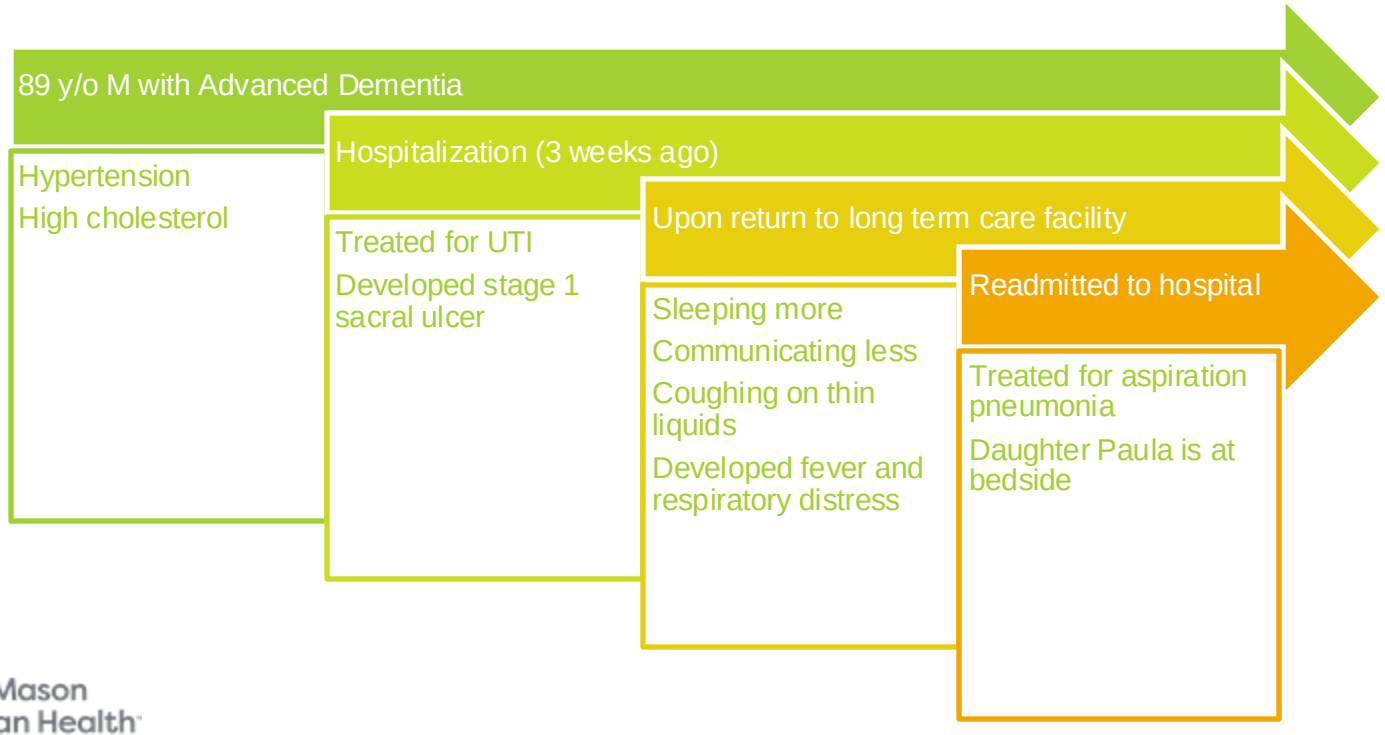
The patient: Mr. B.



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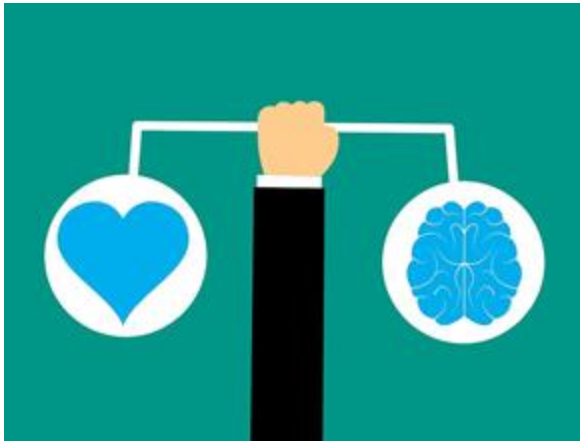
Emotional and cognitive cues



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Definitions:

- Emotional cue–statement tied to an emotion which may not be obvious

- Cognitive cue–statement requesting more information

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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**

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

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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.*

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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/

JAGS 62:1590-1593, 2014 AGS Position Statement

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Family Concerns and Clinician Concerns regarding ANH in advanced dementia

Family concerns

Starve to death
Pain and dehydration
Can’t get strong

Clinician concerns

Recurrent aspiration
Fluid overload
Need for restraints
Infection/bleeding

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Clinician's views on empathy is a barrier

Comer, A et al. Indiana University JPSM June 2020

- 100% clinicians self report that they use empathic statements when engaging with patients (42.1% always 57.9% usually)
  - About 50% believe that stating **“I understand” conveys empathy**
- More that **75% of patients** in previous studies perceive **“I understand”** statements from clinicians as **dismissive** and **disrespectful**
  - Clinicians use “I understand” as a vehicle to move the conversation forward: “I understand this is hard but we also need to talk about …”
  - Instead of “I understand”
  - say “I can’t imagine how hard this is for you

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Why do we eat?

Write top 2 reasons you eat in chat box.

FOOD = LOVE

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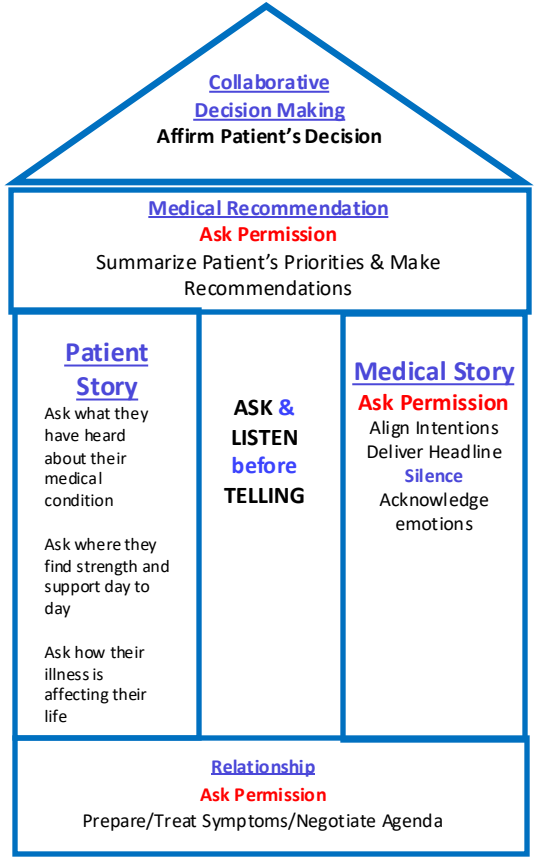
Of the possible options for Mr. B, which is the best match for the reasons most of us eat?

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.



	WAYS	WORDS
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" (15 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?"
Recommend	· 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)

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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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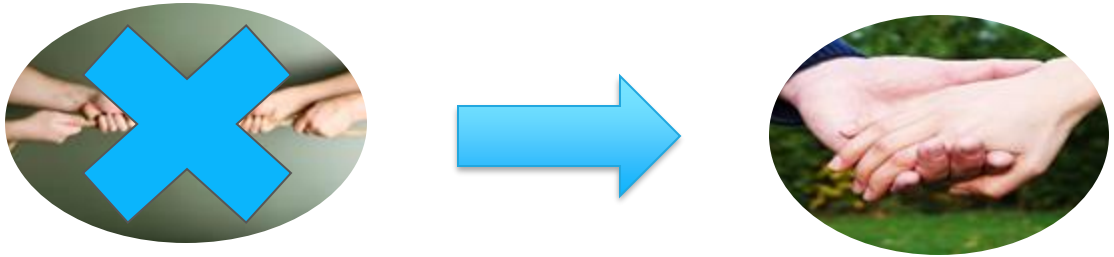
What if Paula doesn't accept your recommendation?



- 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

“I just feel like I’m not ready to give up on the possibility that dad might get better if we feed him.”

Affirm decision: “It sounds like it’s really important to you that we try tube feedings with your dad.”

Time trial: “I’d like to suggest a time limited trial of feedings through a temporary tube X 1 week.”

Specific Endpoint: “If it is helping, we would expect to see your dad being more awake and engaged. We may consider stopping the trial early if your dad develops additional symptoms like agitation or shortness of breath.”

Teach Back: “So that I know I’ve done a good job communicating, can you tell me in your own words what we’ve talked about?”

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Resources

- Wrede-Seaman, Linda, MD, *Symptom Management Algorithms, A Handbook for Palliative Care*, 4th Edition, Intellicard, Inc., 2019
- Back, A., Arnold, R., Tulsky, J., *Mastering Communication with Seriously Ill Patients*, Cambridge University Press, 2009
- Honoring Choices Website (https://www.honoringchoicespnw.org/)
- Dunn, H., *Hard Choices for Loving People*, Sixth Edition, Quality of Life Publishing Co., May 2016-October 2017

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Thank You!!

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