Practical Palliative Care Skills for the ALS/MND Clinician

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Speaker Disclosures

- Research funding from the ALS Association
- Speaking honoraria for this presentation and:
  - Muscular Dystrophy Association
  - ALS Association
  - PMD Alliance

Today’s Agenda

- Brief review of communication skills (15 min)
- Scenarios in breakout rooms (20 min)
- Group discussion and Q&A (20 min)

Objectives

- Definition of Palliative Care
- Describe skills to address serious illness goals of care conversations
- Examples of models to structure goals of care conversations
- Complex symptom management – not covered in this talk

Components of Palliative Care in Neurologic Illnesses

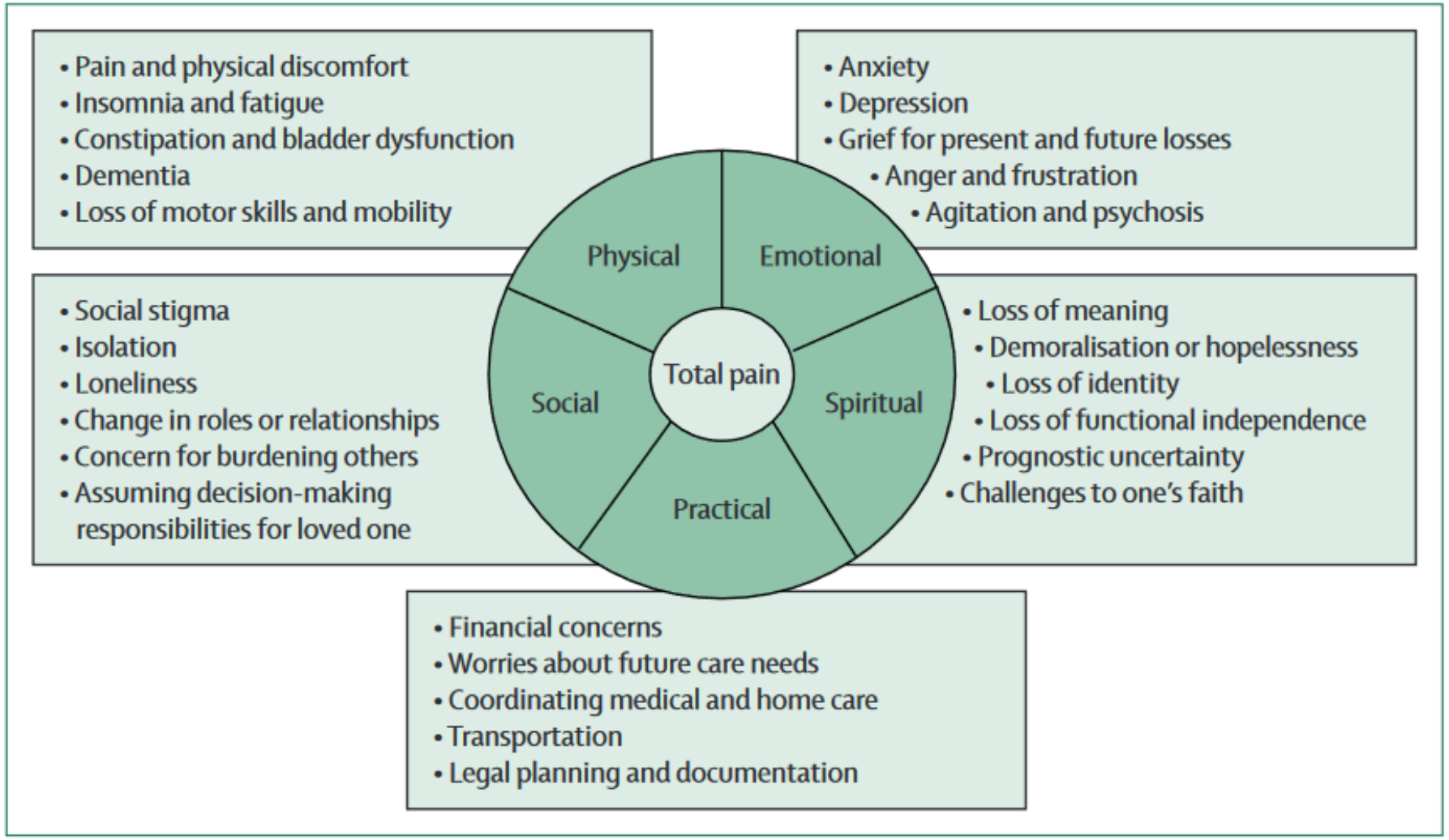
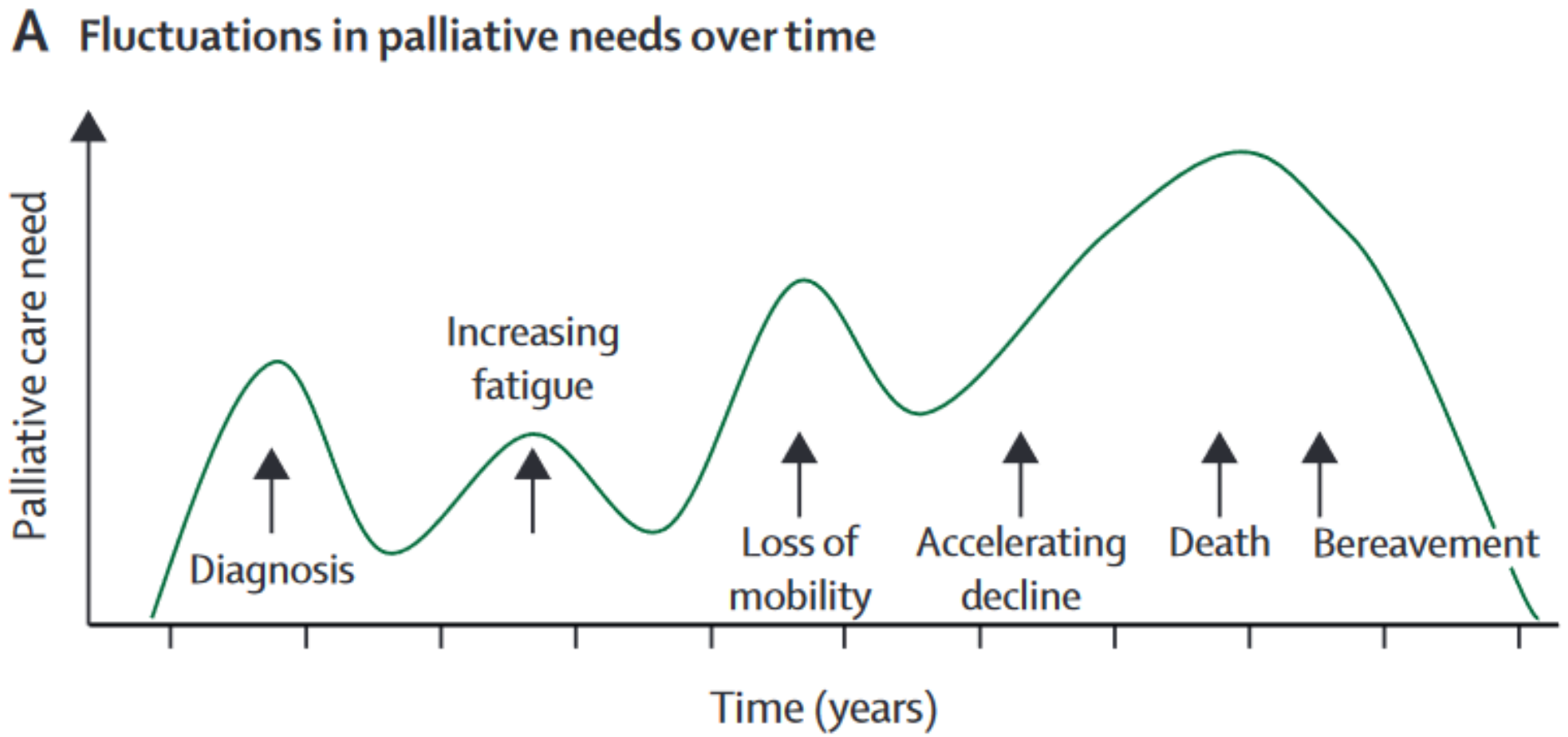


Figure 1: **A model of total pain for neurological disease**

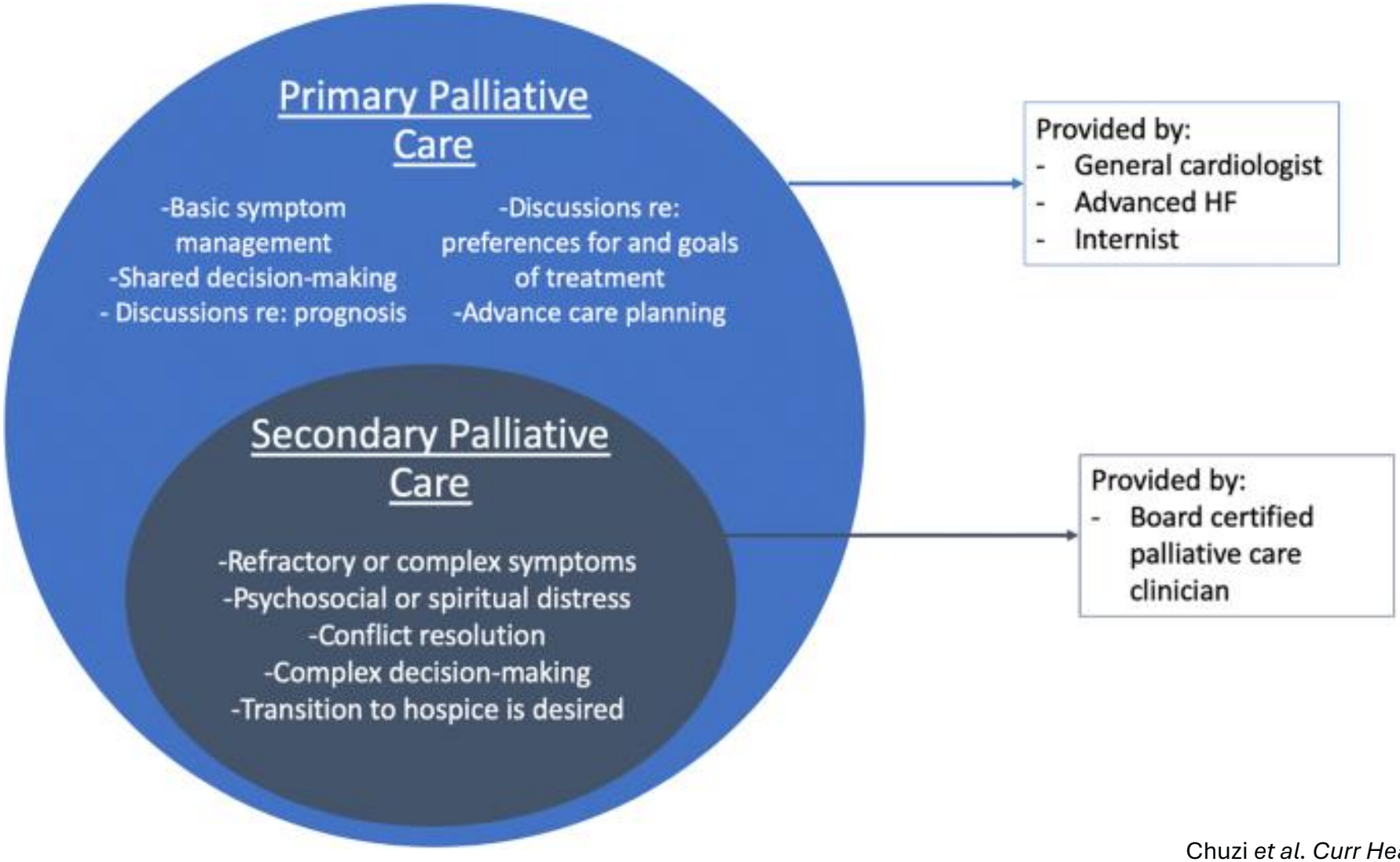
Kluger BM et al. *Lancet Neurol*. 2023



(Neuro)Palliative Needs Fluctuate over Time

Kluger BM et al. *Lancet Neurol*. 2023

Palliative Care Approach



Chuzi *et al. Curr Heart Fail Rep* 2019

Values and Preferences

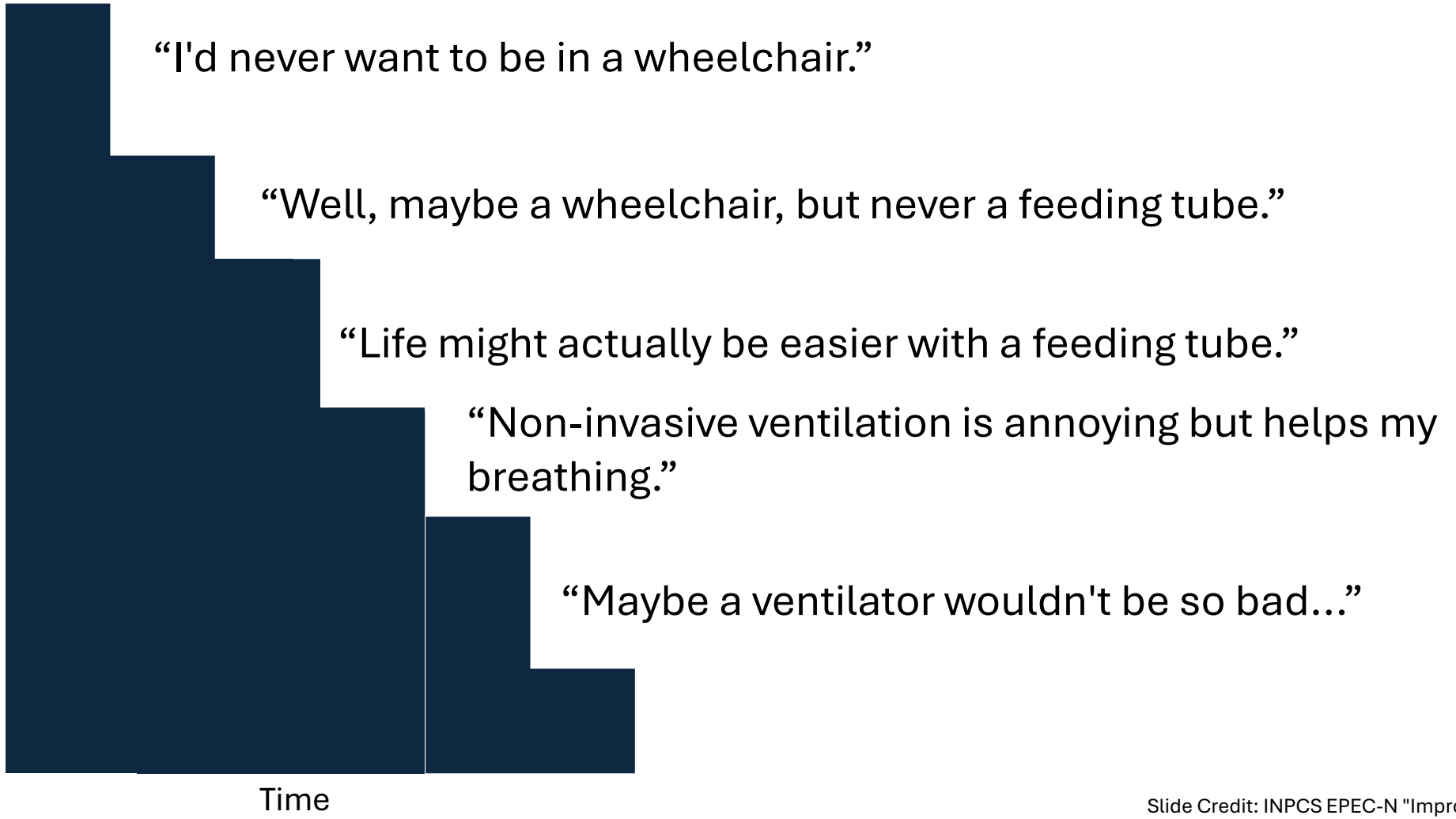
Values: The aspects of life which patients find important

Preferences: Choices that pertains to a specific medical scenario. These are constructed from an individual's core values and influenced by multiple factors

Values + preferences --> patient's goals of care

Slide Credit: INPCS EPEC-N "Improving Medical Decisions" 2022

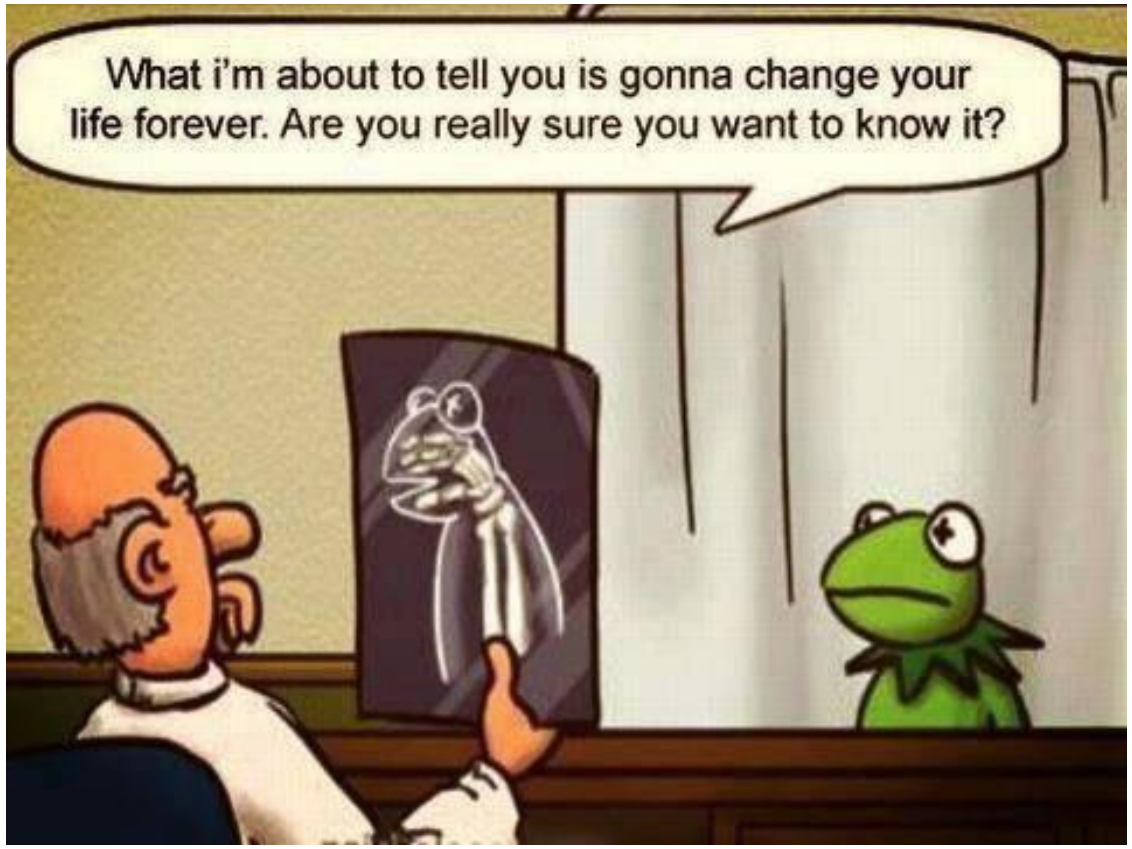
Preferences May Change Over Time



Slide Credit: INPCS EPEC-N "Improving Medical Decisions" 2022

Specific Skills

- Create space to address emotions
- Managing uncertainty
- Time-limited trials
- Asking permission
- Continue to engage in conversations
- Hope/worry statements
- Reflection statements



Examples of Serious Illness Conversation Protocols and Training Programs

- SPIKES
- NURSE
- 3-Act Model
- VitalTalk
- Center to Advance Palliative Care

SPIKES Protocol for Delivering Bad News

Step	Key points	Example phrases
Setting	Arrange for a private room or area. Have tissues available. Limit interruptions and silence electronics. Allow the patient to dress (if after examination). Maintain eye contact (defer charting). Include family or friends as patient desires.	"Before we review the results, is there anyone else you would like to be here?" "Would it be okay if I sat on the edge of your bed?"
Perception	Use open-ended questions to determine the patient's understanding. Correct misinformation and misunderstandings. Identify wishful thinking, unrealistic expectations, and denial.	"When you felt the lump in your breast, what was your first thought?" "What is your understanding of your test results thus far?"
Invitation	Determine how much information and detail a patient desires. Ask permission to give results so that the patient can control the conversation. If the patient declines, offer to meet him or her again in the future when he or she is ready (or when family is available)	"Would it be okay if I give you those test results now?" "Are you someone who likes to know all of the details, or would you prefer that I focus on the most important result?"
Knowledge	Briefly summarize events leading up to this point. Provide a warning statement to help lessen the shock and facilitate understanding, although some studies suggest that not all patients prefer to receive a warning. Use nonmedical terms and avoid jargon. Stop often to confirm understanding.	"Before I get to the results, I'd like to summarize so that we are all on the same page." "Unfortunately, the test results are worse than we initially hoped." "I know this is a lot of information; what questions do you have so far?"
Emotions	Stop and address emotions as they arise. Use empathic statements to recognize the patient's emotion. Validate responses to help the patient realize his or her feelings are important. Ask exploratory questions to help understand when the emotions are not clear.	"I can see this is not the news you were expecting." "Yes, I can understand why you felt that way." "Could you tell me more about what concerns you?"
Strategy and summary	Summarize the news to facilitate understanding. Set a plan for follow-up (referrals, further tests, treatment options). Offer a means of contact if additional questions arise. Avoid saying, "There is nothing more we can do for you." Even if the prognosis is poor, determine and support the patient's goals (e.g., symptom control, social support).	"I know this is all very frightening news, and I'm sure you will think of many more questions. When you do, write them down and we can review them when we meet again." "Even though we cannot cure your cancer, we can provide medications to control your pain and lessen your discomfort."

Baile et al. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist.* 2000

Berkey et al. Delivering Bad or Life-Altering News. Am Fam Physician. 2018

NURSE Mnemonic for Expressing Empathy

Technique	Example phrases
Naming	"It sounds like you are worried about..." "I wonder if you are feeling angry."
Understanding	"If I understand what you are saying, you are worried how your treatments will affect your work." "This has been extremely difficult for you."
Respecting	"This must be a tremendous amount to deal with." "I am impressed with how well you have handled the treatments."
Supporting	"I will be with you during the treatments." "Please let me know what I can do to help you."
Exploring	"Tell me more about your concern about the treatment side effects." "You mentioned you are afraid about how your children will take the news. Can you tell me more about this?"

Back et al. Approaching difficult communication tasks in oncology. *CA Cancer J Clin.* 2005

Berkey et al. Delivering Bad or Life-Altering News. Am Fam Physician. 2018

Summary

Palliative care skills are for everyone

Values are constant. Preferences vary throughout the disease.

The primary skill for a good conversation: listening

Different models are available to help guide the conversation

Breakout Rooms: Questions to consider

1. What are some key phrases or approaches you use when discussing feeding tube placement with patients and families, particularly when there is uncertainty or emotional resistance? How do you ensure the conversation is both clear and compassionate?

2. Can you share an experience where a patient or family requested interventions (e.g., PEG, trach) that the medical team did not believe were beneficial? How do you navigate the tension between respecting patient autonomy and adhering to the principle of non-maleficence?

3. How do you approach cases where a family requests a feeding tube for a patient with cognitive impairment, especially when the patient has an advance directive indicating they would not want AANH? What strategies help you balance the family's wishes with the patient's previously expressed values?

4. How does your team debrief after particularly challenging cases involving feeding tube decisions? How do these debriefs help you manage the emotional and ethical complexities of these cases?

5. How do you address misconceptions, stigma and bad personal experiences surrounding Gtubes?

6. How do you approach situations where a patient who has previously been adamant about not wanting a G-tube changes their decision after experiencing a significant decline in FVC?

7. How does your multidisciplinary team address recommendations and discussions about PEG? For example, do you wait until the neuromuscular specialist recommends it?