

Discussing Feeding Tubes in ALS: Who, When, and How?

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Disclosures

I have received honoraria as an educator for the Muscular Dystrophy Association.

Objectives

- Review significance and causes of weight loss in ALS
- Decisions about feeding tubes and artificial nutrition:
 - To know who can and should have these discussions with patients and care partners
 - To understand when to have these discussions
 - To become familiar with techniques on how to have these conversations

Weight and Appetite Loss

Weight Loss Significance

- Negative prognostic factor – mortality and morbidity
- Rate of weight loss from onset to diagnosis independently related to ALS outcome
- BMI <18.5 kg/m² – 7.7 x higher mortality rate
- 15-55% patients suffer from clinically severe weight loss
- At diagnosis, >10% weight loss prognosis 17 months vs 35 months for <10% weight loss

Causes of Weight Loss

- Malnutrition
- Hypermetabolism
- Cachexia
- Loss of appetite
- Dysphagia

Factors associated with appetite loss in the ALS population



Functional impairment

Anxiety/depression⁵

Duration of disease³

Low ALSFRS-R^{5,19,20}

Older age³



Bulbar-onset disease

Bulbar onset³

Reduced ALSFRS-R bulbar subscale¹⁹



Respiratory impairment

Dyspnea³

Reduced forced vital capacity³



Weight loss

Decreased Body Mass Index^{3,5}

Decreased calorie intake⁹

Low current weight⁵

Weight loss since diagnosis^{3,5,9}

Feeding Tubes and Artificial Nutrition

Quality vs Quantity of Life

- Significantly longer survival with PEG
 - Limb-onset: additional 10 months
 - Bulbar-onset: additional 6.5 months
- Standard of care for survival
- Few data on significant impact for quality of life

Palliative Care

JPSM

NATHAN GRAY, MD



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“As long as I am physically able to watch football, eat ice cream, and criticize my children, THAT is a quality of life I can be happy with.”

What is Palliative Care?

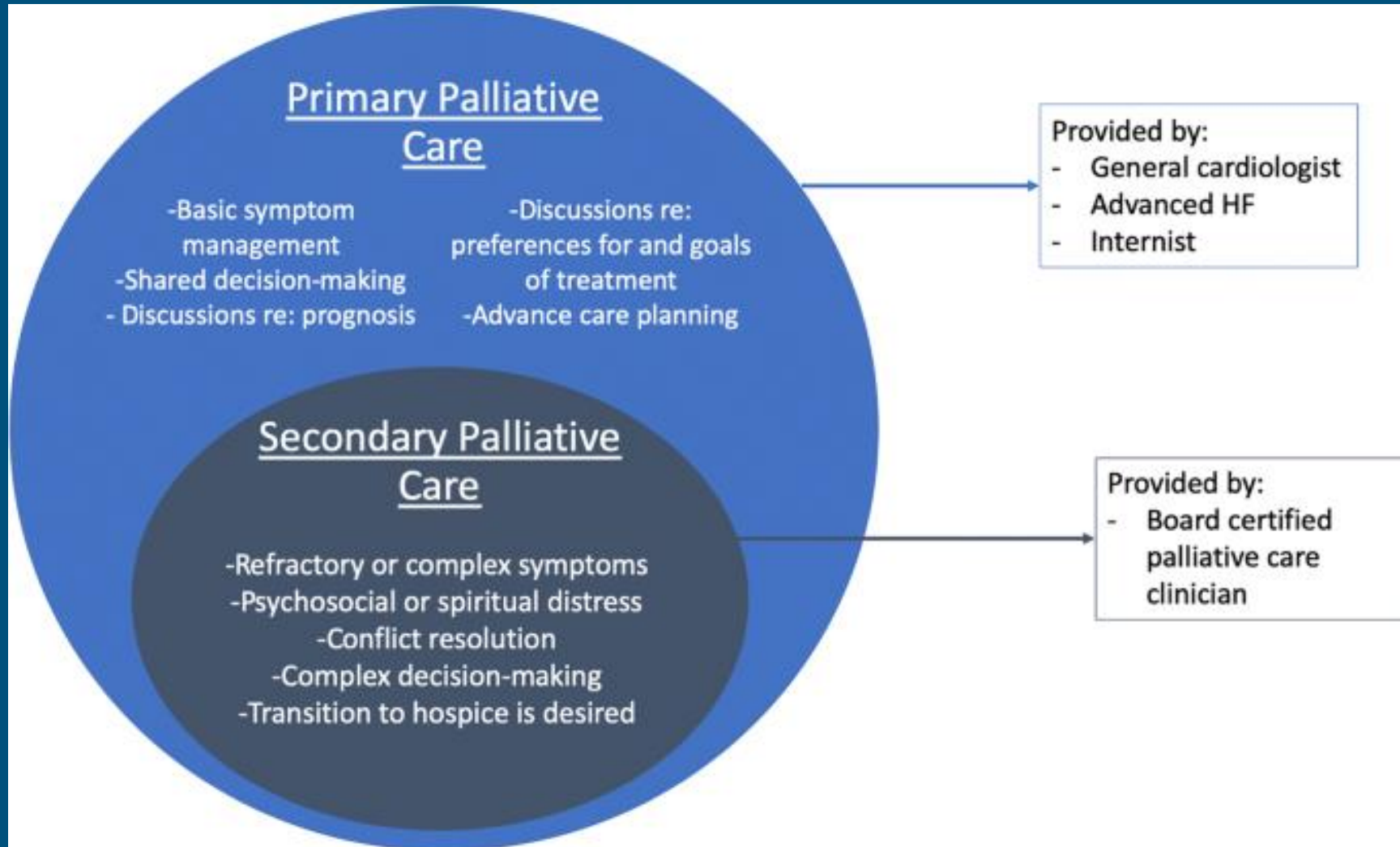
“Palliative care improves the **quality of life** of patients and that of their families who are facing challenges associated with life-threatening illness, whether **physical, psychological, social, or spiritual**. The quality of life of caregivers improves as well.”

– World Health Organization

“**You matter because you are you**, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to **live until you die**.”

– Dame Cicely Saunders

Who Should Be Broaching These Conversations?



Review

Neurology® Clinical Practice

Neurologists as primary palliative care providers

Communication and practice approaches

Claire J. Creutzfeldt, MD; Maisha T. Robinson, MD, MS; Robert G. Holloway, MD, MPH

Take-home points

- *The serious news we discuss with our patients and their families should be tailored to the individuals and their disease; always start by exploring what they already know, what they have heard, and what they understand.*
- *Symptom management in neurologic disease requires particular diagnostic skill given patients' often-impaired cognition and should encompass questions related to any of the palliative care domains of physical, psychological, spiritual, and social needs.*
- *Aligning treatment with patient preferences is at the heart of clinical medicine. While helping the patient and family understand the disease from a medical perspective, the provider should explore who the patient is as a person, what the patient's values are, and what goals the patient wants to set.*
- *Hospice services provide palliative care for patients who are expected to live 6 months or less. This underutilized service can provide optimal end-of-life care to terminally ill people, often in their homes.*
- *A central component of palliative care is the team approach, which involves different professions as well as different disciplines.*

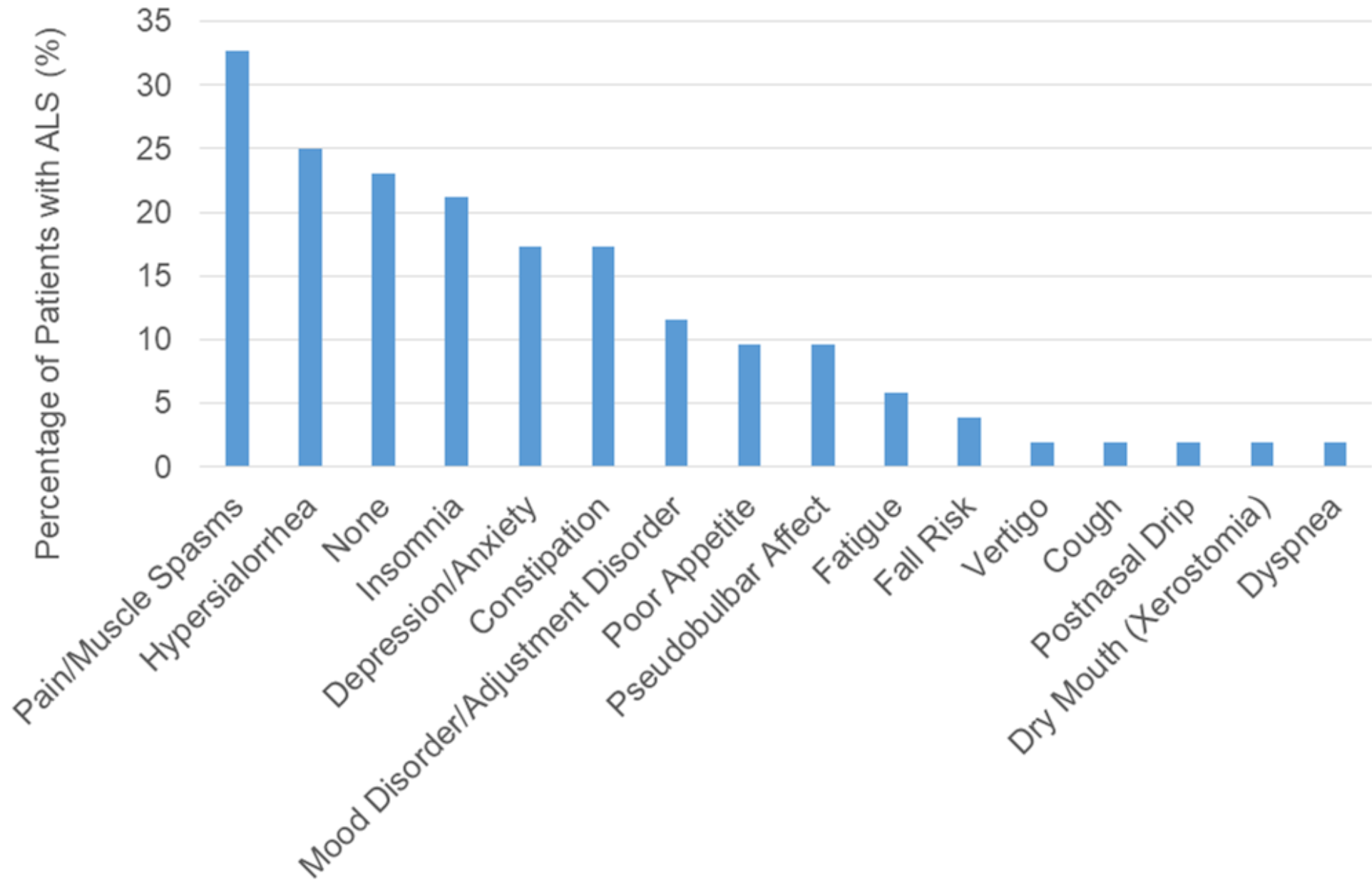
Table 2 Multidisciplinary team members of outpatient care programs for patients with ALS in 6 hospitals across the United States

	Clinical staffing						University of CO (NPC clinic)
	Rush	UCLA	Hauenstein	Cedars-Sinai	Hennepin	University of CO (ALS clinic)	
Neuromuscular physician	X	X	X	X	X	X	
Neuropalliative physician	X	X	X	X	X	X	X
Neuropsychologist				X			X
Advanced practice provider			X			X	X
PM&R physician					X		
Pulmonologist	X			X	X	X	
Association representatives (ALSA and MDA)	X	X	X	X	X	X	
Clinic coordinator				X			
DME representative	X	X	X	X		X	
Genetic counselor				X			
Occupational therapist	X	X	X	X	X	X	
Physical therapist	X	X	X	X	X	X	
Registered dietician	X		X	X	X	X	
Registered nurse			X	X	X	X	X
Respiratory therapist	X	X	X		X	X	
Social worker	X	X	X	X	X	X	X
Spiritual care				X			X
Speech therapist	X	X	X	X	X	X	
Volunteers (patient ambassadors)							X

Abbreviations: ALSA = ALS Association; DME = Durable medical equipment; MDA = Muscular Dystrophy Association.

Specialty Palliative Care





Secondary (Specialty) palliative care

Advance Care Planning	
Code status	21 (40.4%)
Advance directive form (not completed, not on file)	20 (38.5%)
Tracheostomy	18 (34.6%)
Percutaneous endoscopic gastrostomy tube	18 (34.6%)
Prognosis	17 (32.7%)
Hospice	7 (13.5%)
Advance directive form (surrogate decision maker)	7 (13.5%)
Advance directive form (completed prior to visit, not on file)	6 (11.5%)
Advance directive form (completed prior to visit, on file)	6 (11.5%)
Physicians Orders for Life-Sustaining Treatment (POLST) form (completed prior to visit, on file)	4 (7.7%)
Physician aid in dying (End of Life Option Act)	3 (5.8%)
Hospital admissions	2 (3.8%)
POLST form (completed prior to visit, not on file)	0 (-)
POLST form (not completed, not on file)	0 (-)

Goals of Care	
Meaning and values	30 (57.7%)
Family concerns	19 (36.5%)
Coping with diagnosis and disease	18 (34.6%)
Quality of life	10 (19.2%)
Caregiver support	7 (13.5%)
Preferences for receiving information	6 (11.5%)

Limitations of Specialty Palliative Care

- Unclear which physician should take the lead
- Communication limitation
- Cognitive limitation
- Lack of specialists

Box 2 Key barriers to palliative care intervention in non-malignant conditions in Ireland

1. Unpredictable non-cancer disease trajectory
2. Lack of defined referral criteria for non-malignant conditions
3. Lack of non-cancer disease specific expertise
4. Limited resources and high number of potential non-cancer referrals

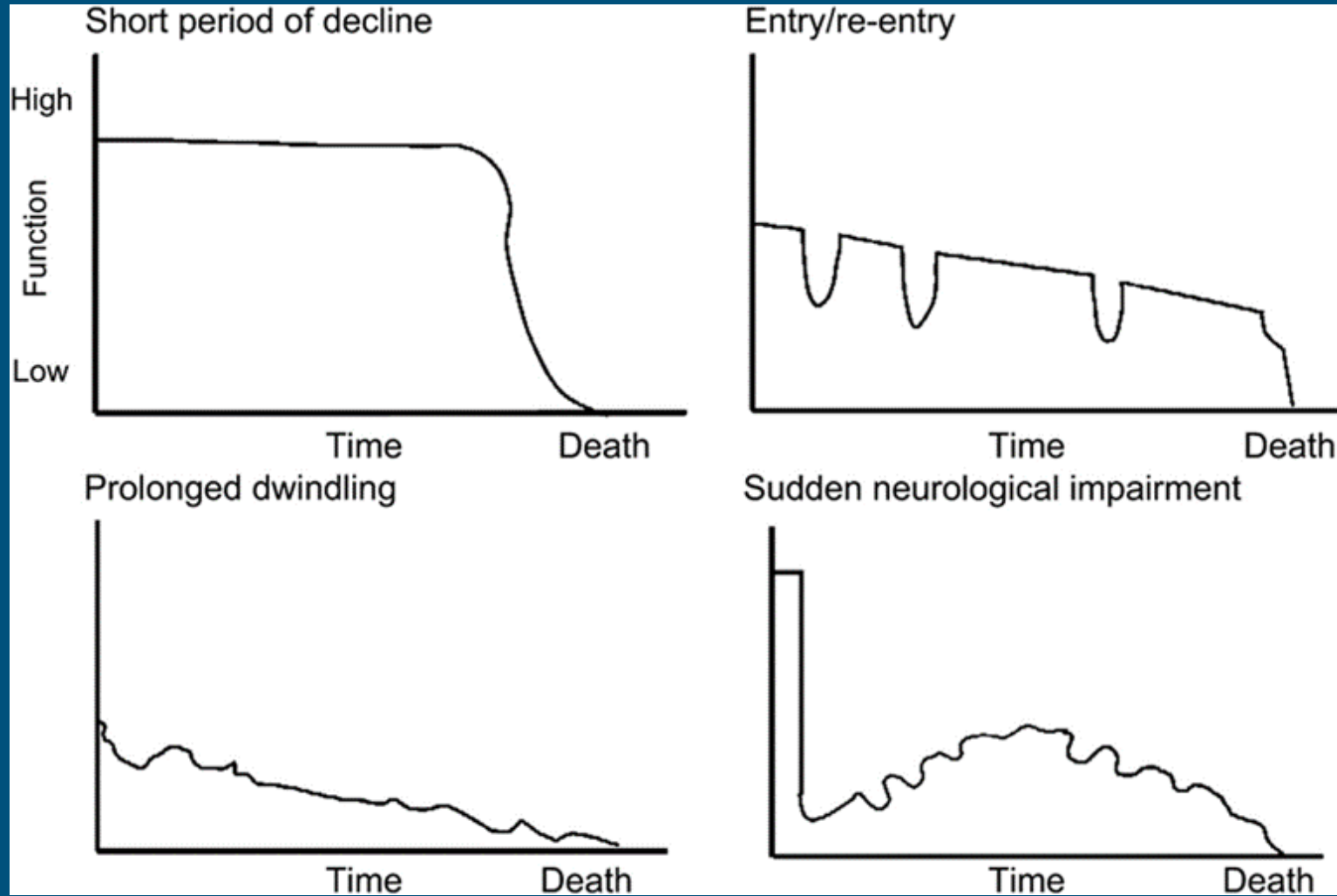
When To Initiate Conversations?

- Timing of PEG placement does not impact survival
- Monitor changes in percent predicted FVC
 - Predicted FVC >50%
- Age of disease onset
- BMI <20 kg/m²
- Recurrent airway secretion accumulation
- Patients dependent on NIV (>16 hours per day)
- **The patient or care partner ask!**

Triggers for Serious Illness Conversations

- New diagnosis of a serious life limiting or chronic life-altering illness
- Change in health or functional status
 - Falls, disease progression, increasing caregiver needs
 - Cognitive impairment
 - Other challenging symptoms such as intractable pain
- Psychosocial issues
 - Caregiver distress, family conflict, hopelessness, difficulty coping
- Signs of poor prognosis
 - Unintended weight loss, recurrent complications or hospitalizations, burden of medications outweighing benefits
- Request for Hastened Death

Prognostication



Poor survival factors

- Risk factors
 - Bulbar-onset (vs limb-onset: more common)
 - Symptom onset after 80 yo (vs before 40 yo: live longer than 10 yrs)
 - Simultaneous frontotemporal dementia
- Some mutations have been associated with shorter survival
- No difference between sporadic and familial ALS
- Shorter time between symptom onset and diagnosis (aggressive disease)

Discussions Around Complex Decision-Making

Existing Methodologies

Technique	Function
SPIKES	6 step process to deliver difficult news
ASK-TELL- ASK	Give medical knowledge
NURSE	Respond to emotion empathically
Open-ended questions	Elicit another person's perspective
Reflection statements	Show that you want to understand another person's perspective
Hope/worry statements	Honestly present information while aligning with person
"Tell me more"	Learn more about another perspective Clarify where the patient is at

Asking for Permission...



Managing Emotions

N.U.R.S.E	Example	Intention
Name	“This is so...” “I can see that this is very...” “This news must be really...”	Acknowledge feeling
Understand	“What is it like to hear this news?”	Helps clarify patient's or care partner's experience
Respect	“You all have done a wonderful job supporting one another.”	Supports patients and/or care partner's work
Support	“We will work through this together.”	Conveys non-abandonment
Explore	“Tell me more about what worries you the most.”	Allows sharing of other concerns

Overcoming Communication Challenges in Neurological Illness

- Communication challenges in neurological illness
 - Cognitive impairment, aphasia, dysarthria
- Allow extra time for conversations
- Consider augmentation with communication devices or pictures
 - e.g. white board, picture board, free-text-to-speech software
- Consider asking simple yes/no questions
 - Opposed to open-ended questions which are typically preferred

Take away points

- Patients with weight loss benefit from feeding tubes.
- Discussions regarding placement of feeding tubes can be led by all healthcare team members – aka You!
- There are prognostic factors and disease characteristics that can serve as triggers for these conversations. Patients and care partners often initiate these conversations.
- Conversation techniques exist and trainings are available.

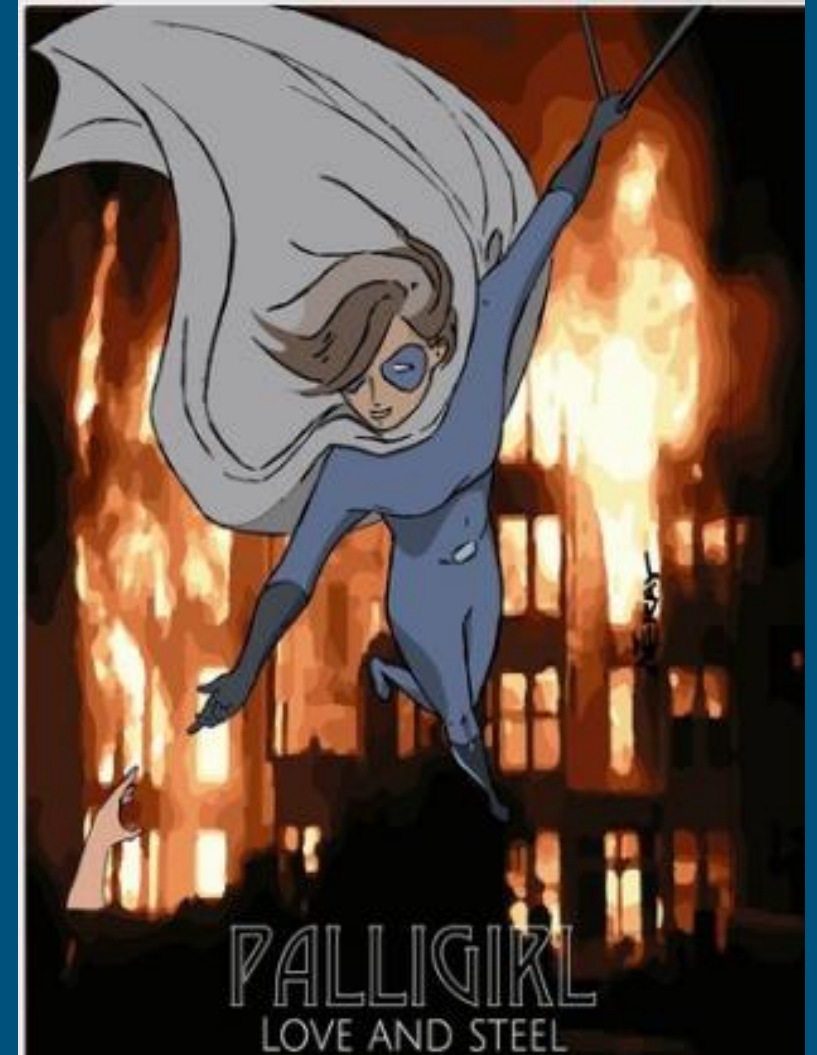


Image by Nathan Gray, MD

Resources

- International Neuropalliative Care Society: www.inpcs.org
- Palliative Care Fast Facts: www.mypcnow.org
- amehta23@jh.edu