

Promoting Personhood and Perspective: Pediatric neuropalliative medicine and the importance of prognostic awareness

Lauren Treat, MD

Assistant Professor of Pediatrics
Child Neurology and Palliative Medicine



MSRGN Virtual Conference
Nov 2023

Disclosures

- I have no relevant financial relationships to disclose and I do not intend to discuss off-label investigative use of a drug / device / product.



Learning Objectives

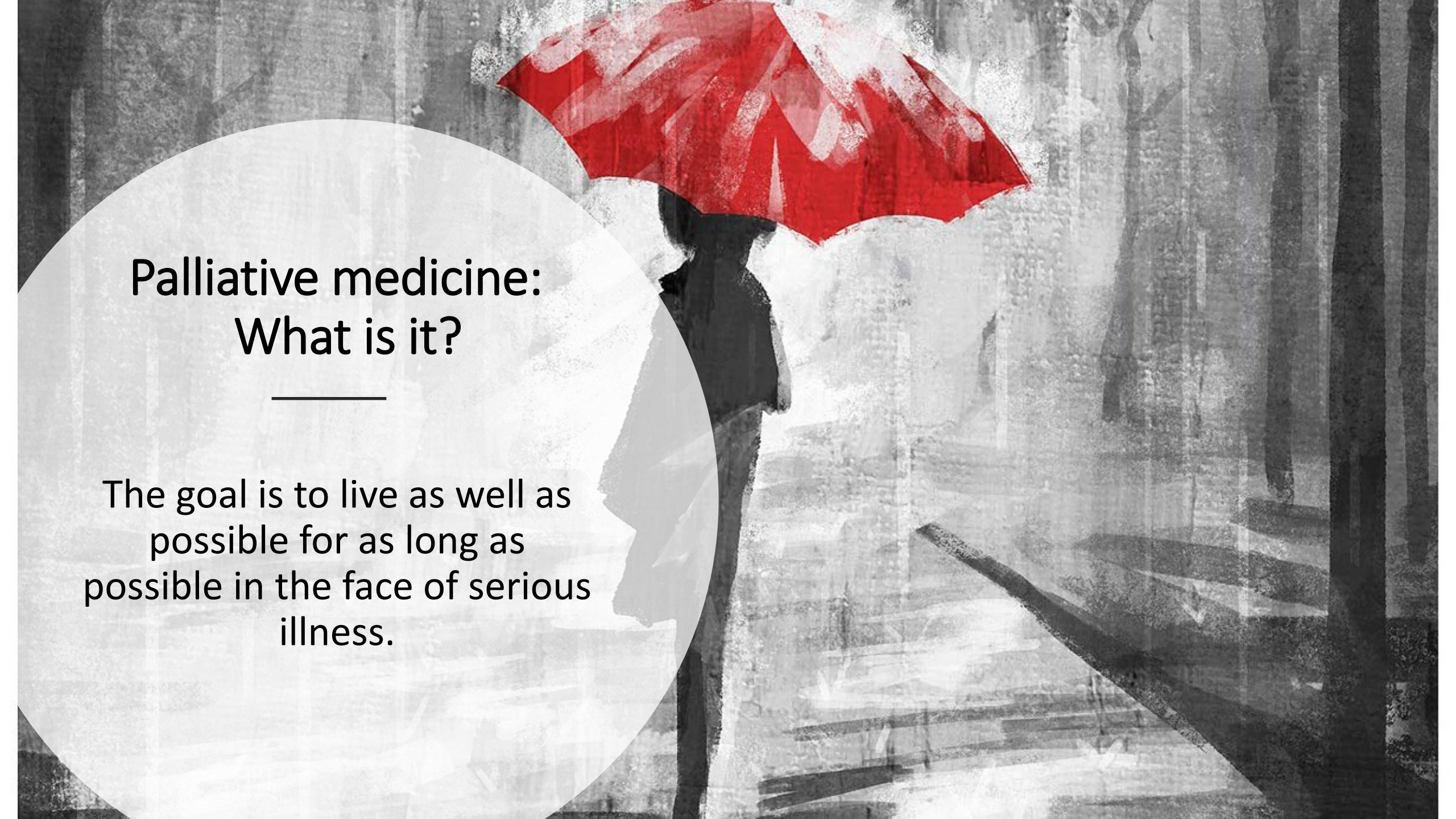
Upon completion of this session, participants will improve their competence and performance by being able to:

- Characterize elements of serious illness family narrative specific to pediatric neurogenetic diseases
- Distinguish mismatch between technological advances and lagging humanistic considerations
- Integrate new tools for serious illness communication



Palliative medicine:

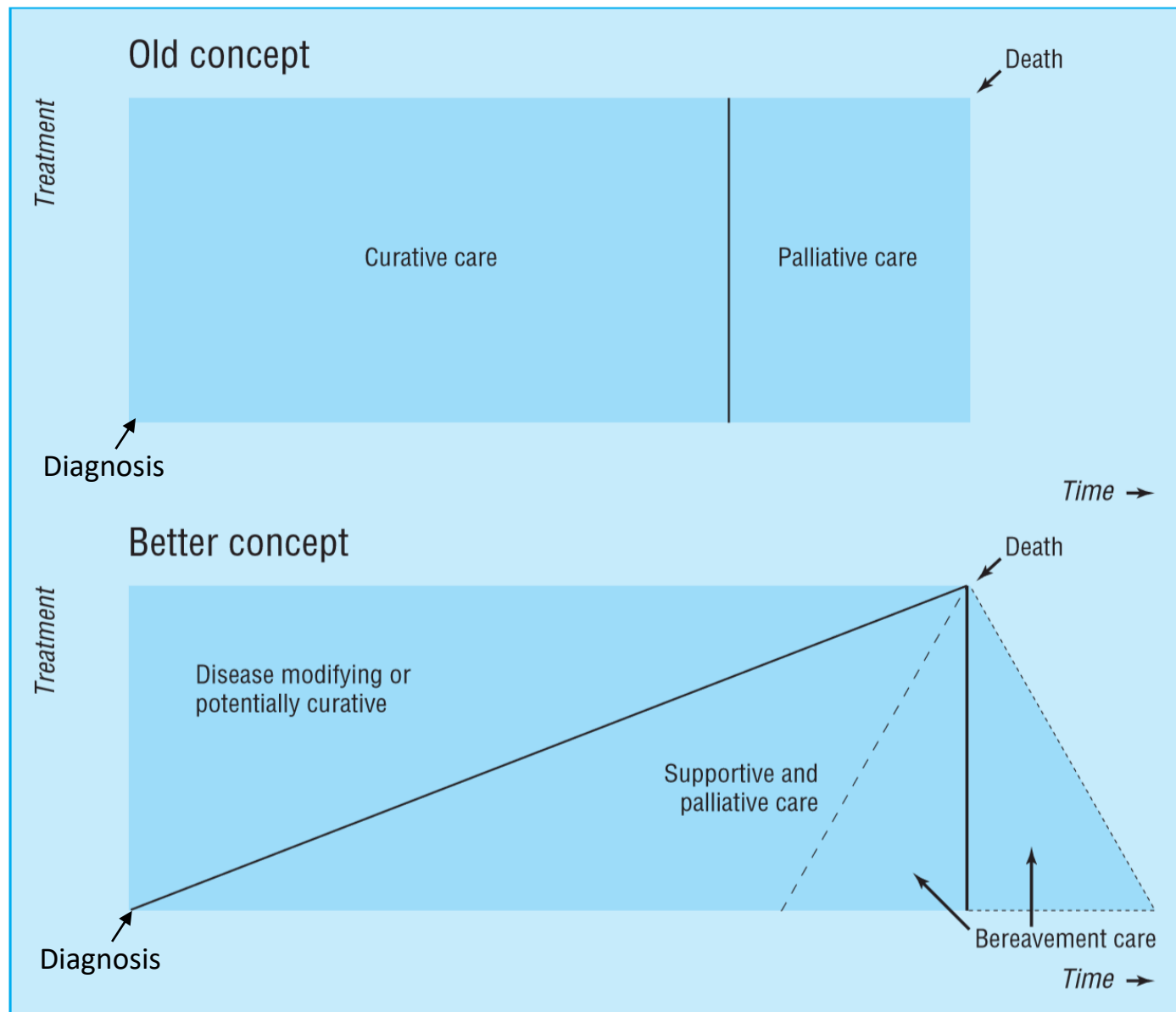
It's not hospice.

A black and white painting of a person holding a red umbrella in the rain. The person is seen from behind, walking away from the viewer. The background is a dark, rainy street with a building on the right. The red umbrella is the only bright color in the scene.

Palliative medicine: What is it?

The goal is to live as well as possible for as long as possible in the face of serious illness.

Palliative medicine: Why the stigma?



Palliative medicine:

What is special about pediatrics?

**Goal-concordant
medical care**

- Adult palliative medicine:
 - Lived values and experience → principles for future decisions

Highest utilizers: Oncology → Neuro dx

- Pediatric palliative medicine:
 - Much less lived experience → expectations for the future
 - Proxy decision making
 - Parental “best interest standard”
 - Consideration of family unit

Highest utilizers: Neuro dx → → Oncology (~20%)

**Parents as
caregivers!**

Palliative medicine:

What is special about neurogenetic conditions?

- Neurological disease
 - Higher rates of disability
 - Multi-system sequelae
 - Prevalence of uncertainty
 - Impact on personhood
 - Existential implications



Palliative medicine:

What is special about neurogenetic conditions?

- Neurological disease
 - Higher rates of disability
 - Multi-system sequelae
 - Prevalence of uncertainty
 - Impact on personhood
 - Existential implications



Increased fragility



Complex grief and relationships

Palliative medicine:

What is special about neurogenetic conditions?

- Neurological disease

- Higher rates of disability
- Multi-system sequelae
- Prevalence of uncertainty
- Impact on personhood
- Existential implications



Increased fragility



Complex grief and relationships

Pediatric neuropalliative care is about helping children with serious neurological conditions live as well as possible for as long as possible, AND requires acknowledgement of the impacts of these unique features on families.

Caring for children with neurogenetic diseases requires tools to acknowledge and manage:

- Uncertainty
- Chronic fragility
- Personhood
- Caregiver exhaustion

Tool: characterize the mindset

Initial Phase

Chronic phase

Peace phase

Focus of Care

Cure

Prolong Life

Live well

Attitude

Beat it

Fight it

Live now

Unpleasantness
tolerance

Very high

High

Low

Emphasis on QOL

Low

Moderate

High

Lived Experience → Prognostic Awareness

Tool: characterize the mindset

	Initial Phase	Chronic phase	Peace phase
Focus of Care	Cure	Prolong Life	Live well
Attitude	Beat it	Fight it	Live now
Unpleasantness tolerance	Very high	High	Low
Emphasis on QOL	Low	Moderate	High

≠ suffering (necessarily)

Caveats:

- Do not misperceive moral weighting
- Do not misjudge hope

Can be mistakenly viewed as "giving up"

Tool: characterize the mindset

	Initial Phase	Chronic phase	Peace phase
Focus of Care	Cure	Prolong Life	Live well
Attitude	Beat it	Fight it	Live now
Unpleasantness tolerance	Very high	High	Low
Emphasis on QOL	Low	Moderate	High

Clinicians have influence & responsibility here, but not control

- Call out what you're seeing in an affirming manner ("It seems like you're doing X so that Y")
- Characterize how likely you think the "payoff" might be ("I'm worried that...")

What would a
“good parent”
do?

- Parents have an internal definition that can be conscious or subconscious
 - Duty to protect, provide, promote, support, guide, etc.
 - Informed by personal experiences, perceptions of others
 - Awareness of these concepts can be important in decision making

Initial Phase

Chronic phase

Peace phase

Focus of Care

Cure

Prolong Life

Live well

Attitude

Beat it

Fight it

Live now

Unpleasantness
tolerance

Very high

High

Low

Emphasis on QOL

Low

Moderate

High

Risk of “Good Parent”
Failure

High

Moderate

Less

Tool: Ask about “Good Parent” narratives

Applications of the concepts

- **Prognostic Awareness**
 - **Impact of early diagnosis via genetic testing**
 - Allows for tailored interventions, connection to resources & other families
 - Generally accompanied by reduced prognostic awareness by families
 - Heightened emotional reaction to news about a difficult future
 - Implications for pre-test counseling

Suggested reading:

Demarest et al, J Child Neurology, Feb 2022

PMID 35196159

Applications of the concepts

- **Prognostic Awareness**
 - Trajectory of illness matters in decision making
 - Progressive illnesses -> parental choices are more comfort-focused
 - Static vulnerabilities (“chronic fragility”) -> parents request continued rescue

Suggested reading:

DeCoursey et al. *J Pediatr* 2018;193:196-203

Applications of the concepts

- Considerations for genetic diseases
 - Decision making about novel therapeutics
 - Weight on families is immense
 - Shared decision making can include a recommendation
 - Parents ask us to share in their burden

Making a path forward

- Attending to the person is just as important as attending to the body!
- Medical community must develop our skills to help manage:
 - Uncertainty
 - Chronic fragility
 - Personhood
 - Caregiver exhaustion

	New Dx Phase	Chronic Phase	Peace Phase
Focus of Care	Cure	Prolong Life	Live well
Attitude	Beat it	Fight it	Live now
Unpleasantness tolerance	Very high	High	Low
Emphasis on QOL	Low	Moderate	High

Lived Experience → Prognostic Awareness



- Skill building resources are available
 - Delivering serious news
 - Communicating prognosis
 - Managing uncertainty
 - Shared decision making



COURAGEOUS
PARENTS
NETWORK

Center to
Advance
Palliative Care™
capc



Anschutz

Masters of Science in
Palliative Care

Pediatric neuropalliative medicine:

Take-aways

- Goal: help people with serious illness live as well as possible for as long as possible, reframe hope over time
- Medical community plays a crucial role in helping build perspective
 - Building prognostic awareness
 - Managing uncertainty
 - Sharing in decision making
- As medicine / technology advances, so too must our human-level interventions

Lauren.Treat@childrenscolorado.org



Affiliated with

School of Medicine

UNIVERSITY OF COLORADO
ANSCHUTZ MEDICAL CAMPUS