DNAR, LOT, POLST – What Does It All Mean?

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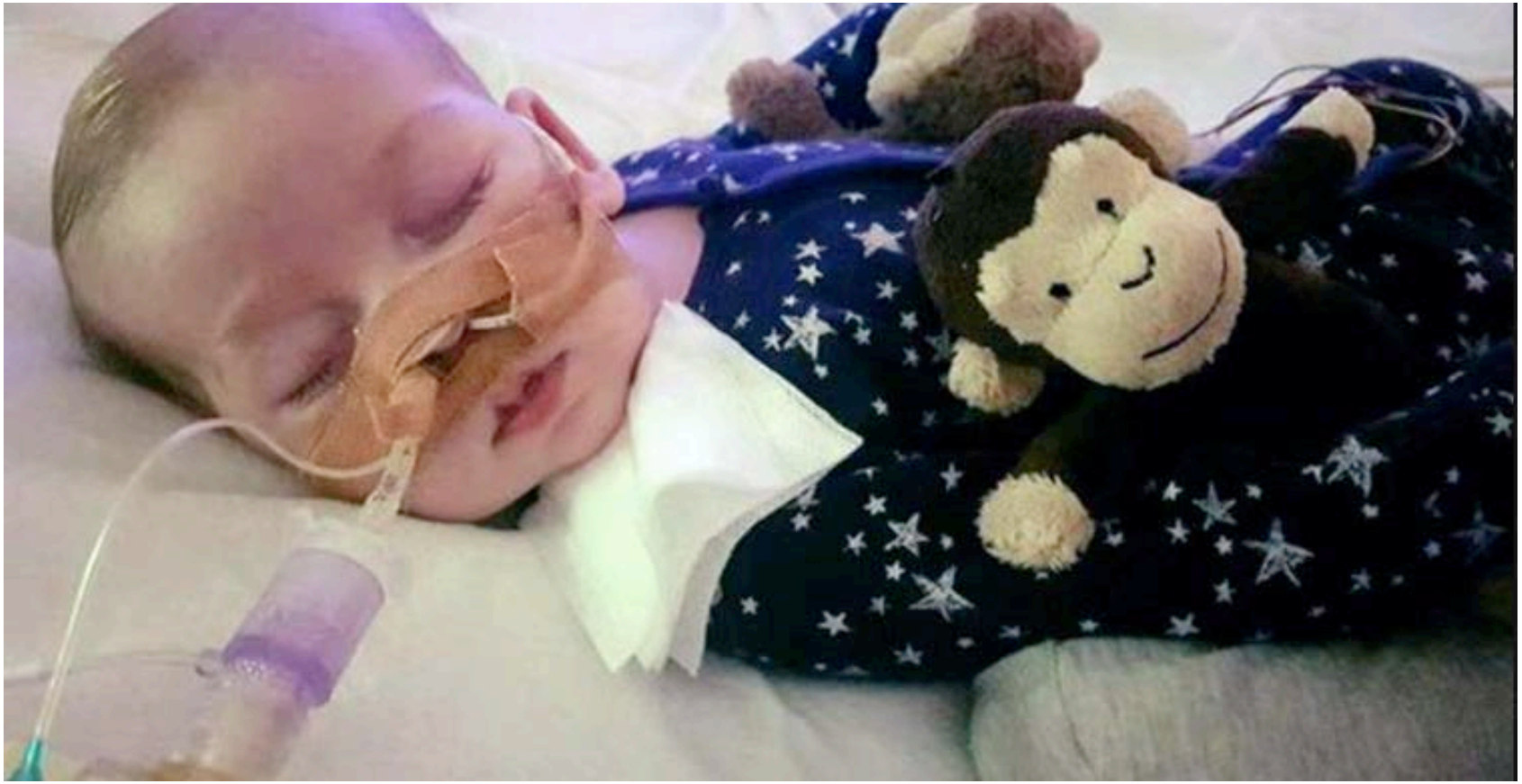
Sadly, Nothing to Disclose

Objectives

- Identify definitions of DNAR, LOT, POLST
- Discuss concepts related to supportive end of life care
- Describe differences and similarities between PC and hospice
- Discuss how to support patient and family navigating end of life situations

Perception

Charlie Gard



Charlie Gard

- Mitochondrial DNA depletion syndrome
- Incurable condition with profound neurologic damage
- Hospital decides not in Charlie's best interest to be kept on ventilator
- Goes to the courts

Question 1

»I agree with the court's decision to remove Charlie from life support.

~True

~False

Question 2

- If Charlie were my child or grandchild, I would choose to withdraw the ventilator.
  - ~True
  - ~False

Charlie Gard

How Do We Help Families?

Pediatrics

- 53,000 US children age 0-19 die each year
- 50% are children < 1 year old
- 75-85% of children die in the hospital, often in ICU
- 500,000 children living with serious illness

Pediatrics

- Congenital defects
- Chromosomal abnormalities
- Acquired devastating injuries
- Malignancies

Different than Adults

- Children aren't supposed to be sick, let alone die!
- Impact of death
- Developmental level of child
  - ~Parents make decisions rather than patient

Barriers to Quality EOL Care

- Realities of life-limiting conditions
- Lack of professional training
- Misunderstanding of Palliative Care
- Failure to acknowledge limits of medicine
- Asking families to stop treatments
- Reimbursement issues

…Barriers

- Gap between MD & parents view of prognosis or QOL
- Primary goal: CURE (not comfort)
- MD's not comfortable with bad news
- Delayed (or non-existent) referral to hospice
- Hospice not comfortable with peds

AAP

- The AAP supports an integrated model of palliative care “in which the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death.”

Aiden

- 6 mo old boy who was previously healthy
- Starting to lose milestones
- Weak, poor feeding

Aiden

- Diagnosed with spinal muscular atrophy (SMA)

Aiden

- First child
- Parents married
- They do lots of research on the internet and ask excellent questions

Helpful Statements

- Acknowledge parental anguish:
  - ~“This must be very difficult for you”
  - ~“This must be a parent’s worst nightmare”
- Avoid statements such as:
  - ~“I know how you feel”

Making Decisions

- Feeding tube
- Trach/vent
- CPR
- Place of death

Video – “We were actively protecting her from things that wouldn’t be right for her”

Question 3

»According to federal law, healthcare teams must perform CPR if demanded by a family.

~True

~False

Question 4

»In most children whom I have coded, it has worked well.

~True

~False

CPR - Right or Rite?

- Rite of passage – a ritual event that marks a person's transition from one status to another
- Rights – legal, social, or ethical principles of freedom or entitlement

Default

- All Americans are “full code” until opt out
- Emergency medical system

CPR

- AHA 1974
- “The purpose of CPR is the prevention of sudden unexpected death. CPR is not indicated in certain situations, such as in cases of terminal irreversible illness where death is not unexpected.”

CPR

- 1986 Guidelines
- “CPR is not usually indicated in the case of the terminally ill patient for whom no therapy for the underlying disease process remains available.”

DNR Orders

- Allows people to opt out
- More accurately DNAR - Do Not Attempt Resuscitation
- Some prefer AND – Allow Natural Death

Autonomy

- Based on negative rights

Survival & Complications

- Hospital patients: 15% survive to discharge
- Chest wall trauma, aspiration: 25-50%
- Persistent Vegetative State: 10%
- Cost to family:
  - ~ Financial
  - ~ Emotional cost of prolonging dying
- Cost to health care team
  - ~ Emotional cost of prolonging dying

Reviving the Conversation Around CPR/DNR

»Historically, the DNR order was an attempt to keep medicine from its implicit quest for immortality. The refusal of a DNR order by a patient continues to operate under the patient choice model—a model that perpetuates the false- hood that all deaths can be prevented and creates the odd and false illusion that all deaths should be prevented.

- Bishop, et al, 2010
- American Journal of Bioethics

Recommendations

- Do not ask “What do you want done if your child’s heart stops or they stop breathing?”
- Make a recommendation
- If patient/family insists, consider ethics consult

Recommendations

- Focus on what WILL be done
- Intensive comfort care
- DNAR does not mean “do not treat”

Question 5

»Children need trachs and g-tubes to be comfortable.

~True

~False

Video – “We created a space where we examined what the Next Steps are”

Hope for the best while preparing for the worst

- Although it may seem contradictory, hoping for the best while at the same time preparing for the worst is a useful strategy…By acknowledging all possible outcomes, patients and their physicians can expand their medical focus to include disease-modifying and symptomatic treatments and attend to underlying psychological, spiritual, and existential issues.
- -Back et al, 2003

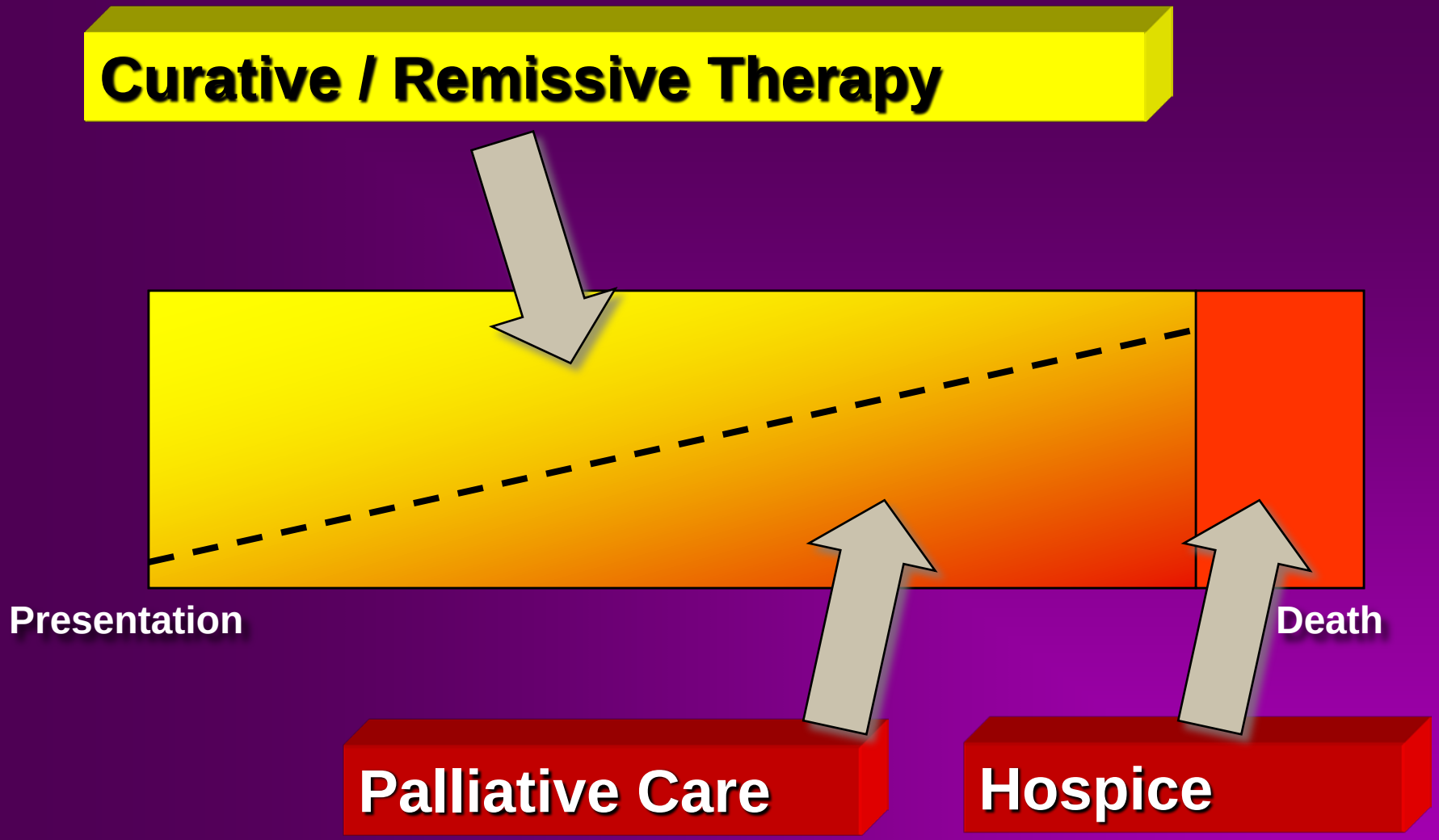
Video – “Palliative Care helps reframe interventions like feeding tubes”

Aiden

- Underwent g-tube and trach placement
- Want to keep him at home as much as possible
- Started getting severe infections

Hospice

- Medicare benefit
- Began in 1970's
- Prognosis less than 6 months
- Must forego life-prolonging, disease-modifying treatments
- Seen as choosing between comfort and cure


Curative / Remissive Therapy
Presentation
Death
Palliative Care
Hospice

Concurrent Care

- Section 2302 of PPACA (2010)
- “Medically necessary treatment services may now be authorized for CCS clients under 21 years of age who have elected hospice care.”
- No longer have to make a choice!

Concurrent Care

- "With concurrent care, a CCS client with a life expectancy of six months or less can enroll in hospice while continuing to receive curative/non-palliative services."
- Provides excellent symptom management & home support
- May continue vent, chemo, TPN, IV abx, blood transfusions

POLST

- Physician Orders for Life-Sustaining Treatment
- California law Jan. 1, 2009
- Helps honors patient/family wishes across treatment settings
- Must be signed by physician and parent
- Voluntary form to complete
- Mandated to follow orders
- Provides legal immunity

Section A

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B
(Effective 4/1/2017)*

First follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. **POLST complements an Advance Directive and is not intended to replace that document.**

Patient Last Name:	Date Form Prepared:
Patient First Name:	Patient Date of Birth:
Patient Middle Name:	Medical Record #: *(optional)*

A *Check One*

CARDIOPULMONARY RESUSCITATION (CPR): ***If patient has no pulse and is not breathing. If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.***

☐ **Attempt Resuscitation/CPR** (Selecting CPR in Section A **requires** selecting Full Treatment in Section B)

☐ **Do Not Attempt Resuscitation/DNR** (Allow Natural Death)

Section B

B *Check One*

MEDICAL INTERVENTIONS: ***If patient is found with a pulse and/or is breathing.***

☐ **Full Treatment – primary goal of prolonging life by all medically effective means.**

In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.

☐ ***Trial Period of Full Treatment.***

☐ **Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.**

In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.

☐ ***Request transfer to hospital only** if comfort needs cannot be met in current location.*

☐ **Comfort-Focused Treatment – primary goal of maximizing comfort.**

Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. ***Request transfer to hospital only if comfort needs cannot be met in current location.***

Additional Orders: _____

Section C

C *Check One*	**ARTIFICIALLY ADMINISTERED NUTRITION:**	***Offer food by mouth if feasible and desired.***
	☐ Long-term artificial nutrition, including feeding tubes.	Additional Orders: _____
	☐ Trial period of artificial nutrition, including feeding tubes.	_____
	☐ No artificial means of nutrition, including feeding tubes.	_____

Section D

INFORMATION AND SIGNATURES:

Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker

☐ Advance Directive dated _____, available and reviewed →
☐ Advance Directive not available
☐ No Advance Directive

Health Care Agent if named in Advance Directive:
Name: _____
Phone: _____

Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)

My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preference

Print Physician/NP/PA Name:	Physician/NP/PA Phone #:	Physician/PA License #, NP Cert
Physician/NP/PA Signature: *(required)*		Date:

Signature of Patient or Legally Recognized Decisionmaker

I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Print Name:		Relationship: *(write self if patient)*
Signature: *(required)*	Date:	Your POLST may be added to a secure electronic registry to be accessible by health providers, a permitted by HIPAA.
Mailing Address (street/city/state/zip):	Phone Number:	

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

Hope

- "Sometimes the best hope is not the hope to save our child but giving our child a comfortable life, well-loved."
  - Sarah & Steve, Emerson's parents

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