# TALKING ABOUT THE END OF LIFE

## **Approaching End-of-Life Planning for Pediatric Patients**

### BACKGROUND

This interactive learning session is part of a curriculum created through a collaboration between Courageous Parents Network and educators at Cleveland Clinic Children's and MassGeneral Hospital for Children. Discussion leaders are encouraged to review the Curriculum Overview Guide and read through this entire Facilitator's Guide when planning the teaching session in order to decide ahead of time which elements to use.

Families whose children suffer from serious illness and the clinicians who care for them often avoid talking about the end of life. No one goes into pediatrics wants patients to die, and the death of a child remains one of the most stressful and difficult situations pediatric clinicians face. Nonetheless, supporting a family whose child is seriously ill and facing the end of life is one of the most important things clinicians are called to do. Opening up conversations anticipating the end-of-life is extremely challenging for many reasons. This learning session is designed to help clinicians think through barriers to and strategies for having end-of-life conversations with patients and families.



### **LEARNING OBJECTIVES**

Through this learning session, participants will:

- Learn to explain barriers to initiating end-of-life planning conversations
- Reflect on personal experiences with introducing end-of-life planning conversations and anticipate challenges faced in doing so
- Consider how Courageous Parents Network videos could be used as a tool for introducing the concept of end-of-life planning to patients and families





IN COLLABORATION WITH



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## **WORKSHOP OUTLINE**

Opening Discussion	5 – 15 minutes
Videos and Discussion	15 – 20 minutes per video
Further Self-Reflection	10 - 15 minutes (to be used in sessions >60 minutes)
Wrap Up/Take Away Messages	5 – 10 minutes
Evaluation	3 – 5 minutes (can also be completed after session)

This chart offers recommendations for which videos to use based on the amount of time you have allotted:

LENGTH OF SESSION	RECOMMENDED VIDEOS
1 hour	1, 3, 4
90 minutes or longer	All videos

Depending on time available, you can share more videos or expand a section of the workshop. We recommend these as minimum amounts of time.

The number of videos you use will depend on the amount of time you have for the learning session. It is helpful to show at least two or three in order to contrast the widely variant experiences of different families. We recommend reviewing all possible videos prior to leading the session to choose those that might resonate most with the group's recent experiences with patients and their families.

## **OPE**

## **OPENING DISCUSSION**

These questions are designed to get participants involved and to help set the stage for the discussion. Depending on the number of participants, this may be best done by talking in groups of two or three. This discussion can be timed for 5 – 15 minutes, depending on how much flexibility you have.

Questions you may pose to the group include:

- Have you been a part of end-of-life planning conversations? Describe an experience you remember from participating in one.
- What events might trigger end-of-life planning conversations among patients, families, and clinicians?
- Why might parents shy away from talking about the possibility their child might die with the medical team? Why might the medical team shy away from talking about this possibility with the parents? What do you think or how do you feel about that hesitation?

### **VIDEOS AND DISCUSSION PROMPTS**

Let the group know that you will show a video and then will allow a few moments of quiet reflection before opening up a brief discussion of their reactions to the video. Discussion prompts are provided to explore themes more deeply.

#### VIDEO 1: "I asked 'So, Lydia, what do you think you would want if you die?'"



Daughter Lydia had Rhabdomyosarcoma (cancer). She died at age 9 after two years of treatment.

#### Video URL

https://courageousparentsnetwork.org/videos/ i-asked-so-lydia-what-you-think-you-wouldwant-if-you-did-die/

- Show video (2:46 minutes)
- **Synopsis:** Paula, mom of Lydia, who died at age 9 from rhabdomyosarcoma, talks about discussing end of life preferences with her nine-year-old daughter, Lydia.
  - Personal silent reflection (30 seconds)
  - Initial reactions from the group (3 5 minutes)
  - Further discussion (10 15 minutes)

#### **Discussion Prompts**

- **a.** What brought about the end-of-life planning conversation for Lydia and Paula?
- b. Have you spent time with a patient and/or his/her family who was comfortable discussing the details of end-of-life preferences? What was it like?
- **c.** How did the end-of-life planning conversations help Paula and her family after Lydia had died?

#### **VIDEO 2:** "She was able to look at me and say, 'Mom, I am dying'"



#### Video URL

https://courageousparentsnetwork.org/videos/ she-was-able-to-look-at-me-and-say-mom-i-amdying/

- **Show video** (1:30 minutes)
- **Synopsis:** Paula, mom of Lydia, who died at age 9 from rhabdomyosarcoma, discusses one of her final conversations with her daughter as Lydia approached the end of life.
  - Personal silent reflection (30 seconds)
  - Initial reactions from the group (3 5 minutes)
  - Further discussion (10 15 minutes)

#### **Discussion Prompts**

- **a.** Have you ever worked with a patient who had this type of clarity at the end of life? If yes, how did his/her parents respond to it?
- **b.** How does Paula talk about the afterlife? How does her belief system help her and Lydia?

### **VIDEO 3:** "Talking to siblings about end of life"



Video URL <u>https://courageousparentsnetwork.org/videos/</u> <u>talking-to-siblings-about-end-of-life/</u>

#### Show video (2:58 minutes)

- **Synopsis:** Courtney Arsenault, Child Life Specialist, discusses how to talk to siblings about the end of life.
  - Personal silent reflection (30 seconds)
  - Initial reactions from the group (3 5 minutes)
  - Further discussion (10 15 minutes)

#### Discussion Prompts

- **a.** Have you ever had to discuss a patient's impending end of life with his/her sibling? What was the experience like for you?
- **b.** What tools or strategies from Courtney's story might you be able to use in your own practice?

#### **VIDEO 4:** "A child can be comfortable right to the end"



Video URL https://courageousparentsnetwork.org/videos/ a-child-can-be-comfortable-right-to-the-end/

- **Show video** (1:40 minutes)
- **Synopsis:** Blyth and Charlie, parents of Cameron, who died at age 2 from Tay-Sachs, describe their realization that a child can be comfortable and pain-free through the end of life.
- Personal silent reflection (30 seconds)
- Initial reactions from the group (3 5 minutes)
- Further discussion (10 15 minutes)

#### **Discussion Prompts**

- a. Have you witnessed peaceful deaths? Was the peace and lack of pain surprising for you, others on the team, or family members?
- **b.** What reflections from Blyth and Charlie's story might you share with a family who is trying to anticipate and talk about their child's end of life?

#### **VIDEO 5:** "Transitioning to end of life – home, hospital, hospice"



#### Video URL

https://courageousparentsnetwork.org/videos/ parenting-a-medically-complex-child-palliativecare-helped-us-plan-his-end-of-life-at-home/

- **Show video** (4:36 minutes)
- **Synopsis:** Brenda, mom of Sam, who died at age 15 after living with medical complexity for his entire life, discusses how she put together the supports her son needed so that he could have his end of life in their home.
  - Personal silent reflection (30 seconds)
  - Initial reactions from the group (3 5 minutes)
  - Further discussion (10 15 minutes)

#### Discussion Prompts

- a. Have you taken care of a patient who chose (or whose parents chose for him/her) to die at home? What kinds of services and supports did that family need to achieve their vision?
- **b.** Have you taken care of a patient who did not want (or whose parents did not want for him/her) to die at home? Why did they feel the way they did?
- c. What insights from Brenda's story might you be able to share with a family who is trying to decide whether to plan for end of life at home?



### **FURTHER SELF-REFLECTION**

If time permits, ask participants to share or briefly journal about their experiences discussing end-of-life big picture and in details with patients and families. Participants should be specifically encouraged to reflect on how the conversation was opened, the degree of formality, and who was involved (or not involved), considering what worked and what did not work in particular cases.



### TAKE AWAY MESSAGES

As a wrap-up, encourage the group to reflect on something they will personally take away from the session. Depending on time and number of participants, ask for a few volunteers to share their take-aways. Some possible themes that you may want to be prepared to discuss include:

- Pediatric patients, parents, siblings, and clinicians can all initiate end-of-life planning conversations. It is possible for initiation of end-of-life planning to come about naturally without an official "meeting" to discuss the topic.
- Triggers for starting end-of-life planning conversations often include disease progression, changes in baseline, escalation of care/interventions, and intensification of home nursing needs.
- Children are often developmentally ready to discuss the end of life, and developmental biases such as "kids don't understand death" or "kids don't need to know" are not helpful.
- Having very frank conversations about the end of life can allay fears of patients and family members and can reassure parents after their child's death.



### FEEDBACK

Please allow a few minutes for your learners to complete the feedback form, available here:

https://www.surveymonkey.com/r/LGXVXSF

And please complete the Facilitator's Feedback form, available here:

https://www.surveymonkey.com/r/CJFTZ9Z



- Five Wishes (must be purchased). <u>https://fivewishes.org/five-wishes/individuals-families/individuals-and-families/children-and-adolescents</u>
- The Conversation Project: Pediatric Starter Kit (free). <u>https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Pediatric-English.pdf</u>
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Primary Author: Amy Saltzman Porter, MD, PhD

**Editors:** Sandra Clancy, PhD Blyth Lord, EdM Shannon E. Scott-Vernaglia, MD Christine Traul, MD