# **MAKING DIFFICULT DECISIONS**

### **Approaching Decision-Making Around Feeding Tubes**

### 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 often face challenging decisions about whether to undertake invasive procedures that intensify care and treatment. For many families, one major turning-point decision is whether to place a feeding tube to support their child's nutrition. Similarly difficult decisions include whether to do a tracheotomy, spinal fusion surgery, and other major surgeries. These decisions are made in the context of a child's illness trajectory and prognosis, both of which influence the extent to which and ways in which outcomes of the intervention may have implications for quality and length of life. Clinicians play an important role in helping families understand what it means to move forward or choose not to move forward with such interventions. For feeding tubes, such an understanding would include the multitude of ways to feed a child, the nutritional and experiential purposes of each, how each type of feeding tube is placed, and alternatives to feeding tubes. This learning session focuses on decision-making around feeding tube placement but is applicable to thinking about turning-point interventions more broadly.



### **LEARNING OBJECTIVES**

Through this learning session, participants will:

- Imagine parents' fears in making decisions about placing feeding tubes
- Reflect on the stories of families that have found feeding tubes helpful AND the stories of families that have found not placing a feeding tube to be the right decision
- Discuss ways in which medical providers can guide families through the decision-making process
- Reflect on personal experiences with patients with placing feeding tubes (or other turning-point interventions) and on how those experiences may shape the ways in which we guide patients and families



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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, 2, 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.

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# **OPENING DISCUSSION**

These questions are designed to get the group 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 flexility you have. You should start by presenting the topic and learning objectives to orient learners.

Questions you may pose to the group include:

- What makes decisions about feeding tubes difficult? For families? For clinicians?
  - What might be a clinician's concerns for patient well-being when these interventions are proposed (e.g. airway stability, nutrition, etc.)?
  - What might be a parent's concerns for patient well-being when these interventions are proposed (e.g. disease progression, prognosis, reversibility of intervention, timeline for intervention and next steps, rehab needs, home care requirements)?
- Who is usually involved in the process of making such decisions?
- How might our personal experiences as family members and/or as clinicians shape how we view families' decision-making experiences and their decisions?

### **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:** "The feeding tube is a difficult decision"



#### Video URL

https://courageousparentsnetwork.org/videos/ the-feeding-tube-is-a-difficult-decision-thereis-no-right-or-wrong/

- Show video (1:11 minutes)
  - **Synopsis:** Cari discusses her experience with her husband, Matt, of exploring whether their daughter, Jessie, should get a feeding tube in the setting of Sanfilippo Syndrome. She reflects on the difficulty of the decision and how there is no right or wrong answer.
    - Personal silent reflection (30 seconds)
    - Initial reactions from the group (3 5 minutes)
  - Further discussion (10 15 minutes)

#### Discussion Prompts

- **a.** Have you been part of a family's feeding tube decision-making process? With the conclusion to pursue a feeding tube? With the conclusion not to pursue a feeding tube?
- **b.** Did the family talk with other families with contrasting views and/or conclusion?
- **c.** Did medical team members help reconcile differing perspectives or decisions? How?



child be hungry"

#### Video URL

https://courageousparentsnetwork.org/videos/ the-doctor-explained-not-doing-a-feeding-tubeisnt-same-as-letting-your-child-be-hungry/ Show video (1:40 minutes)

**VIDEO 2:** "The doctor explained that not doing a feeding tube isn't the same as letting your

- **Synopsis:** Sarah and Steve discuss how their doctor helped them reframe the decision not to place a feeding tube as a reasonable option for their daughter, Emerson, who had Gaucher Disease Type II.
- Personal silent reflection (30 seconds)
- Initial reactions from the group (3 5 minutes)
- Further discussion (10 15 minutes)

### Discussion Prompts

- a. Have you talked with families that feel that deciding not to place a feeding tube (or another turning-point intervention) is akin to neglect or works against their desire to "do everything" for their child?
- **b.** What might have led to their feeling that way?
- **c.** What reasons did those families have for not wanting to do the intervention?
- **d.** For a family deciding against the intervention, what experiences led them to feeling comfortable with that decision?

### **VIDEO 3:** "She needs the G-tube so her body can rest"



Video URL

https://courageousparentsnetwork.org/videos/ she-needs-the-g-tube-so-her-body-can-rest/

- **Show video** (2:01 minutes)
- **Synopsis:** Greg and Heidi, parents of Abby, describe how they think about their daughter's G-tube giving her body a chance to rest.
  - Personal silent reflection (30 seconds)
  - Initial reactions from the group (3 5 minutes)
  - Further discussion (10 15 minutes)

#### Discussion Prompts

- **a.** Why was the physician's framing of "let her body rest" so powerful in the setting of this family's experience?
- **b.** How do the mom and dad in this video approach the narrative of their decision-making process differently?
- c. Imagine a time when offering "rest" to a family might be helpful. What might that look like?

### **VIDEO 4:** "It's about asking the right questions"



Video URL

https://courageousparentsnetwork.org/videos/ re-feeding-tubes-its-about-asking-the-rightquestions/ **Show video** (4:36 minutes)

• **Synopsis:** Parents, Stuart and Jennifer, reflect together with their palliative care provider on the questions they asked and steps they moved through as they decided whether to place a feeding tube for their son, Ben.

- Personal silent reflection (30 seconds)
- Initial reactions from the group (3 5 minutes)
- Further discussion (10 15 minutes)

#### **Discussion Prompts**

- **a.** What do you think the parents and physician in this video mean by "quality of life"?
- **b.** What do the parents and palliative care physician bring up about the meaning of feeding a child by mouth? Does this resonate with you? Why or why not?
- **c.** What additional key questions might you recommend to families (or care teams) as families are deciding about feeding tube placement?



### FURTHER SELF-REFLECTION

If you have more time, ask participants to share or briefly journal about their experiences when families have decided to move forward or not to move forward with a feeding tube or other turning-point intervention. Participants should be specifically encouraged to reflect on what factors contributed to the scenario/outcome and to contemplate ways in which it might have gone differently.



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:

- Families sometimes feel that there is no choice but to move forward with an intervention. Explaining that moving forward is a choice rather than a given can be very powerful in helping families come to the right decision for their child.
- Quality of life must be interpreted by each family choosing an intervention or choosing against an intervention can improve or worsen quality of life, depending on the patient's and family's particular circumstances and what really matters to them.

### **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



### **ADDITIONAL MATERIALS**

- Courageous Parents Network. A Framework for Difficult Decisions. https://courageousparentsnetwork.org/guides/a-framework-for-the-difficult-decisions.
- Courageous Parents Network. *Making Critical Care Choices*. <u>https://courageousparentsnetwork.org/guides/making-critical-care-choices-a-guide</u>.
- Courageous Parents Network. *Tracheostomy Decision Guide*. https://courageousparentsnetwork.org/guides/child-tracheostomy-decision-guide.
- Courageous Parents Network. *Understanding Nutritional Needs*. <u>https://courageousparentsnetwork.org/quides/understanding-nutritional-needs</u>.
- Sarita Singhal, Susan S. Becker, Georgina A. Bojczuk, and Robert D. Baker. 2016. "Tube Feeding in Children." Pediatrics in Review 38 (1): 23-33. <u>https://doi.org/10.1542/pir.2016-0096</u>.

## ADDITIONAL VIDEOS AND DISCUSSION PROMPTS

Following are additional videos relating to making different difficult decisions (other than feeding tube placement).

### **VIDEO 5:** "I always want parents to know they have a choice"



### Video URL

https://courageousparentsnetwork.org/videos/ i-always-want-parents-to-know-they-have-achoice/

### • **Show video** (1:07 minutes)

- **Synopsis:** Janet Duncan, a Pediatric Palliative Care nurse, speaks with mother, Nicky, about anticipating they family's upcoming decisions and being clear that no intervention is essential, that there is always a choice with risks and benefits to either decision.
  - Personal silent reflection (30 seconds)
  - Initial reactions from the group (3 5 minutes)
- Further discussion (10 15 minutes)

### **Discussion Prompts**

- **a.** Have you been a part of conversations where clinicians have not made it clear that a family has a choice or where a family did not feel that they had a choice? How did you feel?
- **b.** How do you think it might help families to have decisions for interventions framed as a choice rather than an inevitable next step? How might this framing make the decision easier or more difficult?

### **TRACHEOSTOMY**

### **VIDEO 6:** "It just wasn't fitting with our family system"



Video URL https://courageousparentsnetwork.org/videos/ tracheotomy-for-my-son/

- Show video (2:05 minutes)
- **Synopsis:** Nicky, the mom of Isaiah and Avery, who both have mitochondrial disease, reflects on the way that a tracheostomy would not be a practical option for her son in the setting of their family situation, emphasizing how she uses the question of what her sons will gain in making decisions about any intervention.
  - Personal silent reflection (30 seconds)
  - Initial reactions from the group (3 5 minutes)
  - Further discussion (10 15 minutes)

#### **Discussion Prompts**

- **a.** How did her discussion of the practical considerations for her family (beyond her son Avery) make you feel?
- **b.** What practical considerations does this mom address in thinking about a tracheostomy? Have you witnessed families reflect on such practical considerations?
- c. What wisdom might you share with other families based on this mom's insights?

### **SPINAL FUSION**

### **VIDEO 7:** "I know I made the best decision because I do not want him living in the hospital"



### Video URL

https://courageousparentsnetwork.org/videos/ spinal-surgery-for-my-son-the-most-difficultdecision-ive-had-to-make/ • Show video (3:24 minutes)

- **Synopsis:** Nicky, the mom of Isaiah and Avery, who both have mitochondrial disease, reflects on the challenges she faced and the uncertainty she continues to face about her decision not to have Avery undergo spinal fusion surgery.
  - Personal silent reflection (30 seconds)
  - Initial reactions from the group (5 minutes)
  - Further discussion (15 minutes)

### Discussion Prompts

- **a.** How do you feel listening to this mom's honest description of her own uncertainty?
- **b.** In what ways might you react to such uncertainty if you hear it from a parent or family member?
- c. What did this mom appreciate about the surgeon with whom she worked?
- d. How do continued inquiries about this decision affect this mom?



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