# BEING A "GOOD PARENT"

### **Helping Families Mitigate Regret**



### **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 are often faced with unimaginable and impossible decisions. This happens in the context of parents' desires to be the best parents they can be for their child. When a child is seriously ill – and decisions that may not have a right or wrong answer must be made – the stakes feel especially high. Research shows that parents of children who have died of cancer report that their sense of having been a "good parent" at the end of their child's life helps them to emotionally survive their experience and their child's loss (October et al. 2014). Clinicians have an important role in helping families mitigate regret about their decisions.

Anchored in family experience through video narrative, this learning session is designed to allow participants the space in which to contemplate parental decision-making and to explore how clinicians can help families mitigate regret about their decisions.



### LEARNING OBJECTIVES

Through this learning session, participants will:

- Explore different ways in which families might experience decision making as it relates to regret, fear of regret, or lack of regret
- Discuss ways in which the medical team might help families mitigate regret about their decisions
- Reflect on how their own experiences and perspectives might differ from those of patients and their families







### **WORKSHOP OUTLINE**

Opening Discussion ...... 5 – 15 minutes

Wrap Up/Take Away Messages ..... 5 – 10 minutes

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.



### **OPENING DISCUSSION**

These questions are designed to get the group involved and to help set the stage for the discussion to come. Depending on the number of participants, this may be best done by talking in groups of two or three.

Questions you may pose to the group include:

- What is regret? What does regret mean to you?
- How do our personal experiences shape how we view others' regret related to 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.

### ${f VIDEO~1}$ : "What we were doing was actively protecting her from things that wouldn't be right for her"



https://courageousparentsnetwork.org/videos/ we-were-actively-protecting-her-from-thingsthat-wouldnt-be-right-for-her/

- **Show video** (2:29 minutes)
- Synopsis: Parents, Sarah and Steve, reflect on the decisions they made for the care of their daughter, Emerson, who had Gaucher Disease Type II. They focus specifically on the decision *not* to do things, framed as "actively protecting her from things that wouldn't be right for her."
  - Personal silent reflection (30 seconds)
  - Initial reactions from the group (3 5 minutes)
  - Further discussion (10 15 minutes)

### **Discussion Prompts**

- a. Have you experienced a time when a family chose not to pursue an offered intervention?
- **b.** Have there been times when a family has pursued treatment because otherwise it would seem to be "not doing anything"?
- c. What do you think about how the palliative care physician supported the parents in this video?

## VIDEO 2: "I will have peace knowing I've done everything as his Mom"



Video URL

https://courageousparentsnetwork.org/videos/i -will-have-peace-knowing-ive-done-everythingas-his-mom/

- **Show video** (1:43 minutes)
- **Synopsis:** Parent, Nicky, speaks about having no regrets in that she has done absolutely everything possible for her son, Avery.
  - Personal silent reflection (30 seconds)
  - Initial reactions from the group (3 5 minutes)
  - Further discussion (10 15 minutes)

#### **Discussion Prompts**

- a. Have you spoken with a parent who feels responsible for keeping a child alive, similar to the mother in this video?
- **b.** Have you encountered families that have felt regret or quilt that they did not do as much as they could to keep their child alive?
- c. How might providers navigate instances in which they see lifeprolonging interventions very differently than a parent sees them?
- d. How might providers caring for Avery and working with Nicky experience her decisions for her child?

### VIDEO 3: "Evaluating does it make sense to run more tests?"



#### Video URL

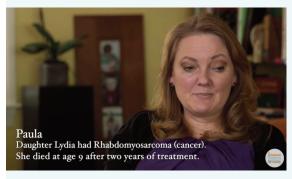
https://courageousparentsnetwork.org/videos/ evaluating-does-it-make-sense-to-run-moretests-in-cases-of-the-cns/

- Show video (3:17 minutes)
- Synopsis: A pediatric palliative care physician who specializes in children with severe neurological impairment, Julie Hauer, talks about the obligation parents and providers both feel to run tests – and how, in the absence of being able to find a cause or being able to treat, we should at least consider NOT running a test, giving parents permission to make this choice.
  - Personal silent reflection (30 seconds)
  - Initial reactions from the group (3 5 minutes)
  - Further discussion (10 15 minutes)

#### Discussion Prompts

- **a.** Have you experienced a time when a family and/or clinical team struggled with the decision about whether or not to continue running tests?
- **b.** Have you witnessed a shift when a clinician offered the team or the family permission to stop running tests?
- **c.** How might we help parents mitigate regret about the decision to stop testing?

### **VIDEO 4:** "Those conversations ended up being my saving grace because then I had no regrets"



#### Video URL

https://courageousparentsnetwork.org/videos/those-conversations-ended-up-being-my-saving-grace-because-then-i-had-no-regrets/

- Show video (1:49 minutes)
- **Synopsis:** Parent, Paula, speaks about how valuable open discussions with her daughter, Lydia, were to her as a means for mitigating regret after she died.
  - Personal silent reflection (30 seconds)
  - Initial reactions from the group (3 5 minutes)
  - Further discussion (10 –15 minutes)

#### Discussion Prompts

- **a.** Have you witnessed or heard a parent talk about a frank conversation with a dying child, such as the one described in this video?
- **b.** Have you encountered family members fearful of having frank conversations with a child about death?
- **c.** What might the value of such conversations be for parents? For children?
- **d.** How might clinicians help parents prepare for and enter into such conversations?

## **FURTHER SELF-REFLECTION**

If you have more time, ask participants to share or briefly journal about their experiences when families have either a) felt/expressed regret; b) communicated "no regrets" type thinking; or c) faced decisions that had the potential to prompt regret. 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.



### 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:

- Parents/family members sometimes feel that not choosing offered interventions and therapies is "doing nothing" and thereby may feel as if they are abandoning their child. Helping parents reframe their decisions as actively protecting one's child can help mitigate regret about such decisions, in the moment and in the future.
- Some parents/family members experience guilt and regret after a child has died at not having "done everything" and many worry about this beforehand. Practicing talking with parents/family members about what they have done/did do to care for their child is an important skill to cultivate.
- Family and care team meetings can help ensure effective planning for caring for children at home, including when it is expected that a child may die at home. It is helpful to orient yourself to your hospital's or affiliated hospice services' resources for such planning.
- Some children and their parents/family members are able and ready to talk openly about death – others are not. Talking with parents/family members about how to prepare for or set-up such a conversation is a potentially very powerful tool for changing how both parties feel as death nears.



### **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. *Framework for the Difficult Decisions*. <a href="https://courageousparentsnetwork.org/quides/a-framework-for-the-difficult-decisions">https://courageousparentsnetwork.org/quides/a-framework-for-the-difficult-decisions</a>.

Brewer, Noel T., Jessica T. DeFrank, and Melissa B. Gilkey. 2016. "Anticipated Regret and Health Behavior: A Meta-Analysis." *Health Psychology* 35 (11): 1264–75. <a href="https://doi.org/10.1037/hea0000294">https://doi.org/10.1037/hea0000294</a>.

Kreicbergs, Ulrika, Unnur Valdimarsdóttir, Erik Onelöv, Jan-Inge Henter, and Gunnar Steineck. 2004. "Talking about Death with Children Who Have Severe Malignant Disease." *New England Journal of Medicine* 351 (12): 1175–86. https://doi.org/10.1056/NEJMoa040366.

Mack, Jennifer W., Angel M. Cronin, and Tammy I. Kang. 2016. "Decisional Regret Among Parents of Children with Cancer." *Journal of Clinical Oncology* 34 (33): 4023–29. <a href="https://doi.org/10.1200/JC0.2016.69.1634">https://doi.org/10.1200/JC0.2016.69.1634</a>.

Meert, Kathleen L., Susan Eggly, Karen Kavanaugh, Robert A. Berg, David L. Wessel, Christopher J.L. Newth, Thomas P. Shanley, et al. 2015. "Meaning Making During Parent-Physician Bereavement Meetings after a Child's Death." *Health Psychology* 34 (4): 453–61. <a href="https://doi.org/10.1037/hea0000153">https://doi.org/10.1037/hea0000153</a>.



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