PALLIATIVE CARE?

Introducing Palliative Care to Pediatric Patients & Families



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 may benefit from palliative care; however, preconceived notions can make the introduction of the team and its services challenging and sometimes unwelcome.

This learning session is designed to explain what pediatric palliative care is and what it has to offer, highlighting the many ways in which parents view palliative care as beneficial to them while caring for their children. We recognize that palliative care at different institutions and in different contexts may include different services, so an introduction to palliative care must be adapted to the family, the power dynamics in the hospital or other caregiving institution, and the reason that palliative care is being considered. Whatever the case, the perspectives of parents who have found palliative care helpful will empower participants to formulate their own, context-specific introductions to palliative care.



LEARNING OBJECTIVES

Through this learning session, participants will:

- Understand the role and value of palliative care in pediatrics
- Explore family experiences with palliative care through video narratives
- Examine scenarios where an introduction to palliative care is appropriate
- Reflect on personal experiences with introducing the palliative care team to patients and families, including challenges and "aha" moments
- Consider how Courageous Parents Network videos could be used as a tool for introducing the concept of palliative care to patients and families





IN COLLABORATION WITH



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, 5 or 4, 6, 7 |
| 90 minutes | 1, 3, 5, 7 |
| 2 hours | 1, 2, 4, 5, 7, +/- 8 |
| Half-day (or longer) workshop | 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. 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:

- What is palliative care?
- How does pediatric palliative care differ from adult palliative care?
- Have you seen pediatric palliative care being introduced to a family, or have you made the introduction yourself? How did it go?
- What can make introducing palliative care challenging for clinicians or upsetting to patients and families?
- Who usually recommends a palliative care referral, and how is this referral communicated to families? Is this the same as or different from referrals to other services?
- Do our personal experiences as patients, family members, and clinicians shape how we view the introduction of palliative care services? How?



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: "Our interdisciplinary team is part of a broader interdisciplinary team"



Video URL

https://courageousparentsnetwork.org/videos/ we-provide-our-expertise-over-the-continuumof-care-and-support-the-broader-team/

- Show video (1:58 minutes)
- Synopsis: Richard Goldstein, a pediatric palliative care physician, describes the interdisciplinary character of the pediatric palliative care team and how the palliative care team can encourage interdisciplinary collaboration within the broader care team.
 - Personal silent reflection (30 seconds)
 - Initial reactions from the group (3 5 minutes)
 - Further discussion (10 15 minutes)

Discussion Prompts

- **a.** Why is interdisciplinary collaboration helpful, particularly in the setting of serious illness?
- **b.** Who is included in an interdisciplinary palliative care team? Anyone you would not expect?

VIDEO 2: "Now I understand what palliative care is!"



Video URL

https://courageousparentsnetwork.org/videos/
now-i-understand-what-palliative-care-is/

- Show video (1:13 minutes)
- Synopsis: Mom, Elizabeth, explains how she came to understand what palliative care is in the context of her daughter, Adelaide's, illness.
 - Personal silent reflection (30 seconds)
 - Initial reactions from the group (3 5 minutes)
 - Further discussion (10 15 minutes)

Discussion Prompts

- **a.** How does this mom define palliative care, and what does she think it has offered her and her child?
- **b.** What are your experiences with helping families think about what the best quality of life is for their child ("everyday" in the words of this parent)?

VIDEO 3: "It was invaluable to hear my wishes mirrored back to me"



Video URL

https://courageousparentsnetwork.org/videos/preserving-his-quality-of-life/

- Show video (1:58 minutes)
- Synopsis: Kerri, mom of Kai, explains how the pediatric palliative care team was helpful in reflecting back to her what she had thought and felt in a different, earlier moment.
 - Personal silent reflection (30 seconds)
 - Initial reactions from the group (3 5 minutes)
 - Further discussion (10 15 minutes)

Discussion Prompts

- **a.** How does this parent define the palliative care team's role as different from other teams' roles
- **b.** Have you seen this type of active listening and mirroring used, or have you used it yourself? Why is it helpful?

VIDEO 4: "Please remind me what's best for him"



Video URL

https://courageousparentsnetwork.org/videos/please-remind-me-whats-best-for-him/

- Show video (2:22 minutes)
- Synopsis: Nicky, mom of Isaiah and Avery, discusses with Janet Duncan, a pediatric palliative care nurse practitioner, how the palliative care team helps her to remember the goals of care she sets for her two sons even as she gets pulled away from those goals by the lure of medical technologies and interventions.
 - Personal silent reflection (30 seconds)
 - Initial reactions from the group (3–5 minutes)
 - Further discussion (10 15 minutes)

Discussion Prompts

- **a.** What role does the palliative care team play for this mom? Why is the resource beneficial for her?
- b. Have you seen a palliative care or other team remind a family of the goals of care they set out previously? Did that reminder influence that family's decision-making? Did it influence clinicians' decision-making?

VIDEO 5: "Palliative care is about being able to provide them with hope and also being able to provide them with comfort and the courage they need"



Video URL

https://courageousparentsnetwork.org/videos/ we-provide-parents-with-hope-and-also-thecourage-they-need-to-take-the-journey/

- Show video (1:46 minutes)
- Synopsis: Tracy-Larson Benvenutti, an in-home palliative care social worker, talks about how palliative care intends to provide hope balanced with comfort and courage.
 - Personal silent reflection (30 seconds)
 - Initial reactions from the group (3 5 minutes)
 - Further discussion (10 15 minutes)

Discussion Prompts

- **a.** Why is the message about hope so important throughout the trajectory of a serious illness?
- **b.** How have you seen clinicians provide hope? Comfort? Courage? Were there particular words that stood out to you?
- **c.** How have you seen clinicians balance hope with realistic expectations?
- **d.** Have you experienced times when you or other clinicians have helped families to be courageous?

VIDEO 6: "To create a space where you can examine what next steps are"



Video URL

https://courageousparentsnetwork.org/videos/ we-created-a-space-where-we-examined-whatthe-next-steps-are/

- Show video (2:28 minutes)
- Synopsis: Parents, Stuart and Jennifer, and pediatric palliative care physician, Pat O'Malley, consider what the introduction of pediatric palliative care offered to the family as they made decisions.
 - Personal silent reflection (30 seconds)
 - Initial reactions from the group (3 5 minutes)
 - Further discussion (10 15 minutes)

Discussion Prompts

- a. How might the framing of palliative care's role as "to create a space" make it easier for clinicians and families to talk about palliative care?
- b. Do you think this concept of creating space would resonate with any families with whom you have worked or are currently working? Why or why not?

VIDEO 7: "We are interpreters"



Video URL

https://courageousparentsnetwork.org/videos/palliative-care-gave-us-a-language-to-talk-to-the-medical-specialists/

- **Show video** (2:05 minutes)
- **Synopsis:** Parents, Stuart and Jennifer, and pediatric palliative care physician, Pat O'Malley, reflect on how palliative care helps families develop language to communicate with clinicians, as well as space to reevaluate and rethink decisions already made.
 - Personal silent reflection (30 seconds)
 - Initial reactions from the group (3 5 minutes)
 - Further discussion (10 15 minutes)

Discussion Prompts

- **a.** Have you seen families change their decisions over time? How has this been communicated with the clinical team? Have they ever been wary to communicate this?
- **b.** Have you seen families that had difficulty communicating their hopes and wishes to the clinical team? Why was it difficult?
- **c.** What language does palliative care offer that encourages and facilitates communication between families and the clinical team?

VIDEO 8: "I wish somebody told us to get palliative care at the beginning"



Video URL

https://courageousparentsnetwork.org/videos/ i-wish-somebody-had-told-us-about-palliativecare-at-the-beginning/

- Show video (1:19 minutes)
- Synopsis: Greg and Heidi, parents of Abby, reflect on how palliative care would have been helpful at the time of diagnosis.
 - Personal silent reflection (30 seconds)
 - Initial reactions from the group (3 5 minutes)
 - Further discussion (10 15 minutes)

Discussion Prompts

- **a.** How is early introduction of palliative care helpful to patients and families?
- **b.** In comparing early introduction versus later introduction of palliative care, how might timing influence families' experiences of their children's care?

FURTHER SELF-REFLECTION

If you have more time, ask participants to share or briefly journal about their experiences introducing or watching others introduce palliative care. Participants should be specifically encouraged to reflect on timing, definitions, setting, and modality (e.g. written materials, internet resources, in person conversations), as well as what worked and what did not work.



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 palliative care is ideally offered at the time of diagnosis with a life-threatening disease or at a shift in baseline in the case of a long-term chronic condition. An early introduction is optimal, as it allows the team to develop a trusting relationship with the family and accompany them through all turning points in care, as well as eventually transition to end-of-life care. This is the gold standard of pediatric palliative care.
- Pediatric palliative care caregivers include physicians, NPs, nurses, social workers, chaplains, art and music therapists, child life, and others. The team is truly interdisciplinary.
- Mirroring families' feelings, including hopes and fears, and thought processes is an especially
 useful aspect of palliative care. This skill is invaluable for caregivers working with children
 with chronic complex medical conditions.



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. *Guidelines for the Conversation(s)*. https://courageousparentsnetwork.org/quides/quidelines-for-the-conversations.

- The American Academy of Pediatrics. 2013. "Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations. Section on Hospice and Palliative Medicine and Committee on Hospital Care. Policy Statement." PEDIATRICS. https://doi.org/10.1542/peds.2013-2731.
- Bogetz, Jori F., Christina K. Ullrich, and Jay G. Berry. 2014. "Pediatric Hospital Care for Children with Life-Threatening Illness and the Role of Palliative Care." *Pediatric Clinics of North America*. https://doi.org/10.1016/j.pcl.2014.05.002.
- Davies, B., S. A. Sehring, J. C. Partridge, B. A. Cooper, A. Hughes, J. C. Philp, A. Amidi-Nouri, and R. F. Kramer. 2008. "Barriers to Palliative Care for Children: Perceptions of Pediatric Health Care Providers." *PEDIATRICS*. https://doi.org/10.1542/peds.2006-3153.
- Kaye, Erica C., Jared Rubenstein, Deena Levine, Justin N. Baker, Devon Dabbs, and Sarah E. Friebert. 2015. "Pediatric Palliative Care in the Community." CA: A Cancer Journal for Clinicians. https://doi.org/10.3322/caac.21280.
- Madden, Kevin, Joanne Wolfe, and Christopher Collura. 2015. "Pediatric Palliative Care in the Intensive Care Unit." Critical Care Nursing Clinics of North America. https://doi.org/10.1016/j.cnc.2015.05.005.
- Weaver, Meaghann S., Katherine E. Heinze, Katherine P. Kelly, Lori Wiener, Robert L. Casey, Cynthia J. Bell, Joanne Wolfe, Amy M. Garee, Anne Watson, and Pamela S. Hinds. 2015. "Palliative Care as a Standard of Care in Pediatric Oncology." *Pediatric Blood and Cancer*. https://doi.org/10.1002/pbc.25695.



Primary Authors:Patricia O'Malley, MD
Amy Saltzman Porter, MD, PhD

Editors:

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