

THE POWER OF THE FAMILY VOICE

Using Courageous Parents to Teach Clinicians



OVERVIEW

This open access curriculum has been created through a collaboration between Courageous Parents Network and educators at Cleveland Clinic Children’s and MassGeneral Hospital for Children. We ask that anyone utilizing the curriculum provide feedback through the evaluation links below.

Understanding the patient and family perspective and communicating effectively with families are essential to pediatric clinical practice. It is particularly important for clinicians to support and collaborate with families caring for children with complex and life-limiting illness. While clinical trainees gain hands-on experience working with families and learn from mentors who model these practices for them, there is often a gap when it comes to more formal teaching about these topics.

This curriculum was designed to help close that gap.

Utilizing the voices and experiences of patients and families as catalysts for learning can be incredibly powerful for adult learners. Much of the learning from patient families traditionally included in training programs happens as part of the clinical care environment. Competing clinical demands can limit learners’ opportunities to explore their own feelings or questions about parent and family decisions. There is, however, a golden opportunity for trainees to learn from patient families outside of the clinical care delivery system that is often underutilized. This series of learning activities is grounded in the “family voice” and families’ experience of serious, life-limiting pediatric illness through the medium of video first-person narrative.

The workshops in this series are designed to explore some of the key aspects of families’ experiences of care for their seriously ill children. They can be used as stand-alone teaching sessions or as part of a longitudinal curriculum.



**COURAGEOUS
PARENTS
NETWORK**

www.courageousparentsnetwork.org

IN COLLABORATION WITH



MassGeneral Hospital
for Children

Cleveland Clinic Children’s Hospital



VIDEOS

The video narratives included in this curriculum have been developed and curated by Courageous Parents Network. They are powerful, short video clips of parents speaking about their personal experiences as parents of children with serious illness. For each learning activity, we have chosen a few videos from the large CPN collection. We encourage educators and learners to explore the full library of videos, as these are but a few of the rich collection available online at <https://courageousparentsnetwork.org/>.



CREATING A SAFE LEARNING ENVIRONMENT

Central to the effectiveness of this curriculum is the creation of a safe learning environment. Participants should be invited to share vulnerability in the discussions, but that must be done in a setting in which they feel psychologically safe. Facilitators must set ground rules for the discussion in order to do so. We encourage you to review the ***Touchstones*** developed by the Center for Courage and Renewal as a model for this.

On occasion, hearing a family's story or engaging in the discussion may evoke powerful emotions in participants. Facilitators should be prepared for this and allow participants to step away if needed.

We strongly discourage forced participation. Discussion leaders should work to invite participation from all, but not require it. Often breaking participants into small groups for parts of the discussion can better allow space for learners to share their thoughts and reflections.



LAYOUT OF WORKSHOP GUIDES

Each workshop guide is laid out in a similar fashion. You will find the following elements:

- **Background:** The main topic of the workshop and why might it be important.
- **Learning Objectives:** The anticipated learning outcomes from the session.
- **Workshop Outline:** A rough timeline and suggested videos to use based on the time allotted for the workshop.
- **Opening Discussion:** Discussion prompts set the stage for watching the videos and help establish a safe learning environment.
- **Videos and Discussion Prompts:** We have chosen several videos that touch on the theme of the workshop. Each video has a link, synopsis, and discussion prompts.

- **Further Self Reflection:** A self-reflection/journaling prompt is provided. This may be used in the session when there is time or alternatively used as a take-home reflection exercise if desired.
- **Take Away Messages:** Some expected key take away points are provided. To wrap up the session, facilitators are encouraged to have participants reflect on what they have learned.
- **Additional Materials:** Additional resources and reading for facilitators and learners.



EVALUATION

This curriculum is freely shared with all interested clinician educators and learners. In return, we ask that all facilitators and participants complete short after workshop evaluations. Survey links are below and paper surveys are available upon request. We welcome educators to also contact us by email at connect@courageousparentsnetwork.org with questions and suggestions.

- **Facilitator survey:** <https://www.surveymonkey.com/r/CJFTZ9Z>
- **Learner survey:** <https://www.surveymonkey.com/r/LGXVXSf>



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