

SUPPORTING SIBLINGS

Caring For and Supporting the Siblings of Patients with Complex Medical Needs



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 faced with a unique emotional burden. Siblings often experience feelings of abandonment; fear of getting sick, too; and survivor guilt. Furthermore, when a child is diagnosed, much of the attention is appropriately shifted to that child. Healthy siblings of children with complex medical conditions are in a particularly difficult situation and are often unintentionally overlooked. Siblings may be expected to take on caregiver roles within the family at a young age, and may experience a decline in quality of life, as well as a loss of attention and status within the family. Parents may feel guilt about this, which becomes yet another burden for them.

This learning session is designed to teach the importance of supporting healthy siblings – and their parents – through their siblings' medical journeys.



LEARNING OBJECTIVES

Through this learning session, participants will:

- Learn to articulate the difficulties families encounter in helping siblings understand their siblings' illnesses
- Understand the siblings' perspective
- Describe ways in which medical providers can help build support systems for families and siblings



**COURAGEOUS
PARENTS
NETWORK**

www.courageousparentsnetwork.org

IN COLLABORATION WITH



MassGeneral Hospital
for Children

Cleveland Clinic Children's Hospital



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, 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. 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 types of stressors are families are facing when trying to care for their healthy children, while another child is seriously ill?
- When caring for patients with complex medical conditions, have you thought about their healthy siblings? Have parents asked for your advice on how to support them?
- In what ways have you seen medical providers support families and healthy children?



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: *"It is important to talk from the beginning about the other children"*



Video URL

<https://courageousparentsnetwork.org/videos/its-important-to-talk-from-the-beginning-about-the-other-children/>

- **Show video** (4:42 minutes)
- **Synopsis:** Nancy Frumer Styron, pediatric psychologist and grief counselor, stresses the importance of acknowledging that there are many ways in which healthy siblings will be influenced. Floribel and Eduen, parents of Bela, share their perspective on how their younger daughter's illness may have affected their older sons. Blyth and Charlie Lord, parents of Cameron, tell about the professional counsel they received about what to tell their two-year old daughter about her baby sister's illness.
 - 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 families about their lives outside of the hospital? Describe your conversations.
 - b. Have you experienced parents asking for advice in caring for their healthy children? What resources could be helpful?
 - c. What advice would you give to parents asking about caring for their healthy children?

VIDEO 2: *"Helping siblings cope, from the siblings"*



Video URL

<https://courageousparentsnetwork.org/videos/helping-siblings-cope-from-the-siblings/>

- **Show video** (1:48 minutes)
- **Synopsis:** Siblings of children with complex medical conditions discuss what it's like to have a brother or sister with a serious illness.
 - Personal silent reflection (30 seconds)
 - Initial reactions from the group (3 – 5 minutes)
 - Further discussion (10 – 15 minutes)
- **Discussion Prompts**
 - a. As a child, did you personally have or know someone who had a sibling with chronic illness? What do you recall feeling?
 - b. How do you feel the age of the sibling relative to the patient would change the challenges and perhaps your approach to the family?

VIDEO 3: “Child life supports siblings”



Video URL

<https://courageousparentsnetwork.org/videos/child-life-supports-siblings/>

- **Show video** (2:23 minutes)
- **Synopsis:** A child life specialist, Courtney Arsenault, talks about how she and her team work with siblings to help them figure out what it means to be the sibling of a seriously ill child.
 - Personal silent reflection (30 seconds)
 - Initial reactions from the group (3 – 5 minutes)
 - Further discussion (10 – 15 minutes)
- **Discussion Prompts**
 - a. Consider different ways in which child life specialists, social workers, music or art therapists, and others can help siblings understand the complex or chronic patient's illness.
 - b. Consider different ways that parents can help siblings understand the complex or chronic patient's illness.
 - c. In what ways does this inspire you to approach families of complex or chronic patients differently, to help support siblings?

VIDEO 4: “Her sharp decline was hardest on her brother; he thought they had more time”



Video URL

<https://courageousparentsnetwork.org/videos/her-sharp-decline-was-hardest-on-her-brother-he-thought-he-had-more-time/>

- **Show video** (2:48 minutes)
- **Synopsis:** Cari, mother of Dylan and Jessie, speaks candidly about how the younger brother experienced his sister's fast decline. His one regret was not being able to say “good-bye” when she was still alert and engaged.
 - Personal silent reflection (30 seconds)
 - Initial reactions from the group (3 – 5 minutes)
 - Further discussion (10 – 15 minutes)
- **Discussion Prompts**
 - a. What did you hear the mother saying about what was difficult for her son?
 - b. Notice how this piece really sticks with the mom. Could the end-of-life experience have gone another way?



FURTHER SELF-REFLECTION

If you have more time, ask participants to share or briefly journal about their experiences with siblings of children with chronic illness.



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:

- It is important to talk from the very beginning about the other children. It is never too early to bring them into the discussion.
- It is helpful to be honest with siblings about what is going on, at an age-appropriate level.
- Help parents to carve out specific time for their other children. Remind them that it is ok to leave the hospital.
- Help parents seek help! Child life specialists, social workers, and psychologists are all excellent resources to guide families through these difficult times



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 Parent's Guide to Helping Siblings Cope*.

<https://courageousparentsnetwork.org/guides/helping-siblings-cope>.

Courageous Parents Network. *Dividing getting out, staying in, and accepting help*.

<https://courageousparentsnetwork.org/videos/dividing-getting-out-staying-in-accepting-help/>.

Courageous Parents Network. *Helping siblings cope, from the parents*. (video)

<https://courageousparentsnetwork.org/videos/helping-siblings-cope-from-the-parents/>.

Courageous Parents Network. *Parents need to own how stretched they are*.

<https://courageousparentsnetwork.org/videos/parents-need-to-own-how-stretched-they-feel/>.

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Knecht, Christiane, Claudia Hellmers, and Sabine Metzger. 2015. "The Perspective of Siblings of Children with Chronic Illness. A Literature Review." *Journal of Pediatric Nursing* 30 (1): 102–16. <https://doi.org/10.1016/j.pedn.2014.10.010>.

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