

December 3, 2019 • Talks on Tuesdays Webinar

Family Centered Care: The Grief Continuum

PRESENTED BY
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8

TODAY'S PRESENTER



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9



10

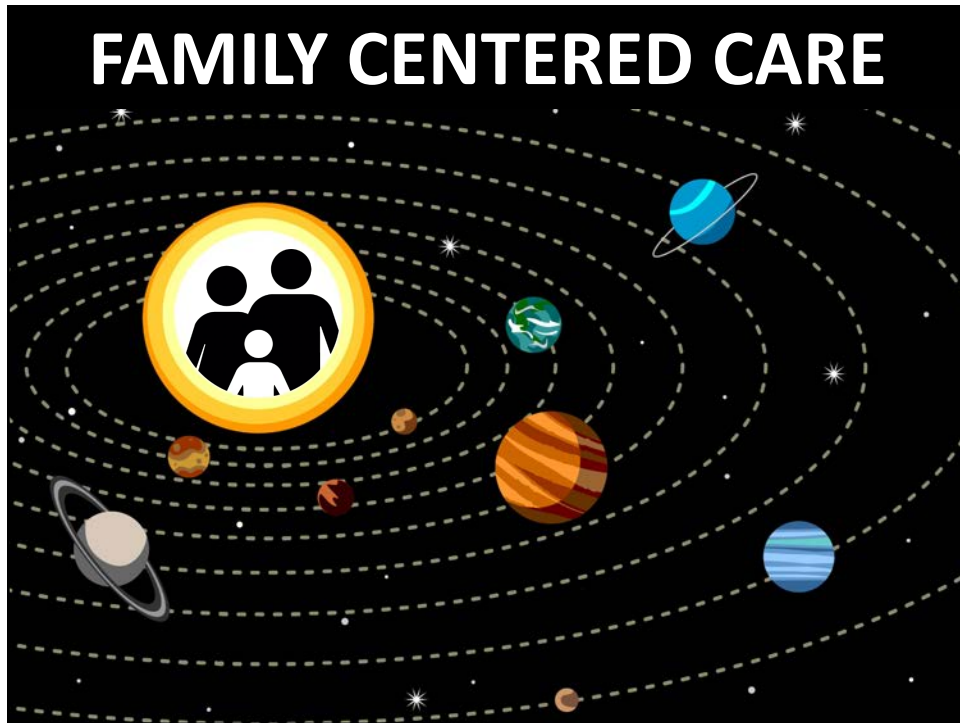
LEARNING OBJECTIVES

Understand Family-Centered Care tenants that provide a foundation of support when responding to the needs of children and families experiencing grief.

Understand Anticipatory grief, and grief as typical responses when faced with a loss: new diagnosis, life-altering change, and/or transition to end of life care and bereavement.

Learn what parents with lived experience have to say about their needs along the continuum and how providers can respond in ways that help families cope and hope.

11



12

Elements of Child and Family Centered Health Care

(ELNEC Pediatric Palliative Care – 2003)

1 Family as Constant

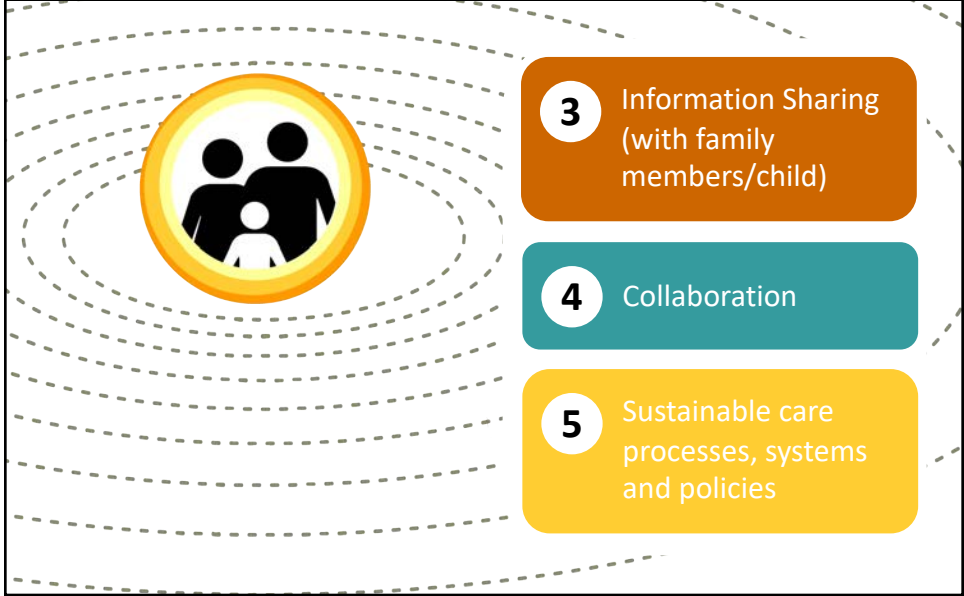
2 Family has Strengths

The diagram features a central family icon (two adults and a child) inside a yellow circle, surrounded by concentric dashed lines representing orbits. To the right, there are two callout boxes. The first is a blue rounded rectangle with the number "1" in a white circle, followed by the text "Family as Constant". Below this is a photograph of a family of four (two men, one woman, and a child) sitting on the grass outdoors. The second callout box is a grey rounded rectangle with the number "2" in a white circle, followed by the text "Family has Strengths".

13

Elements of Child and Family Centered Health Care

(ELNEC Pediatric Palliative Care – 2003)



3 Information Sharing
(with family members/child)

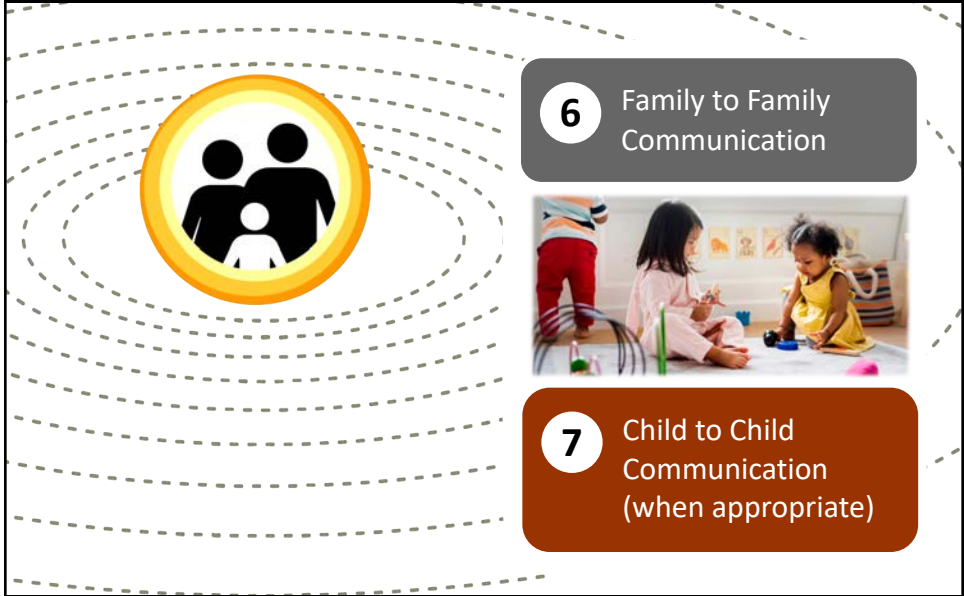
4 Collaboration

5 Sustainable care processes, systems and policies


14

Elements of Child and Family Centered Health Care

(ELNEC Pediatric Palliative Care – 2003)



6 Family to Family Communication



7 Child to Child Communication
(when appropriate)

15

“From a healthcare perspective you need to go in there waiting to see what they bring to you and not bringing what you have. Seeing what the family makeup is and seeing the different roles people have in the family and then supporting them any way that you can, versus bringing your structure into their home, because it doesn’t tend to work very well.”

(Sibling, interviewed in Browning 2002)

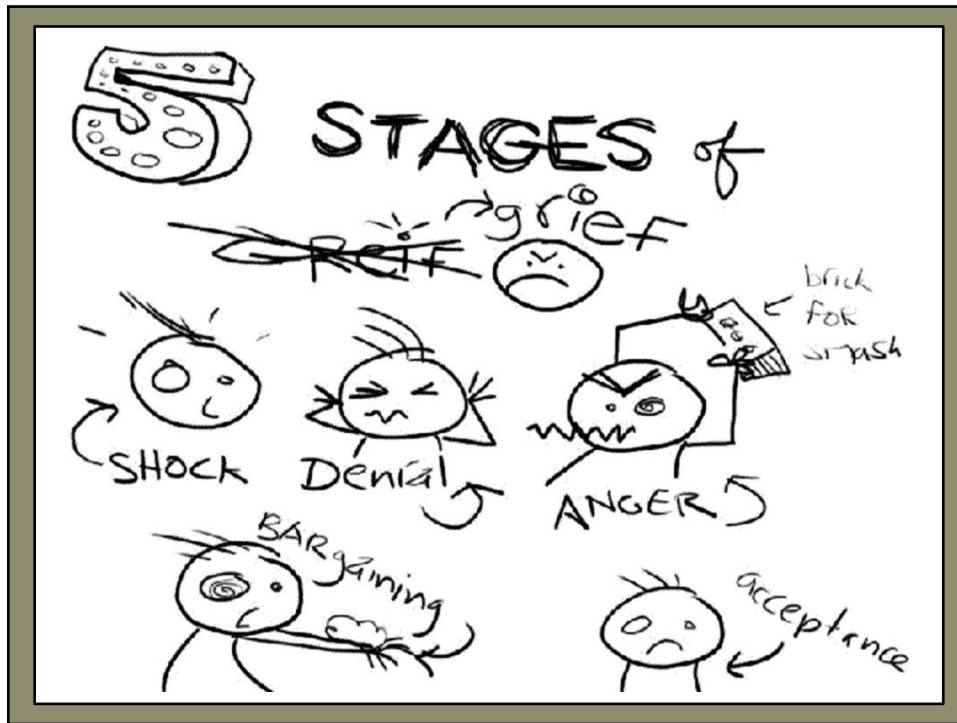
16

“People are like animals; they have different attributes. My husband was like a bear protecting his cub. It is just what a parent needs to do sometimes. I was an ostrich but eventually came up for air. Just hang in there with me, I need your help.”



Statement from parent (Child Life Focus)

17



18



19



Loss:
the event

Anticipatory Grief:
anticipated and real losses associated with the diagnosis, missed milestone, illness, death

WHAT IS GRIEF?

Grief:
the reaction to the event
(physical/emotional)

Mourning:
the process of adapting
to the loss

Bereavement:
experiencing the grief and
actively mourning

20

What do families need when they are experiencing loss and grief?



Share your response in chat.

21

You have been working with Shen, 2 ½ years, and his family for several months. You have just received a phone calling saying their child has died. Shen had neuroblastoma, an aggressive cancer, and had been receiving treatment. Shen was hospitalized many times, but always seemed to rally. The parents are obviously devastated. Although, the type of cancer has a very poor prognosis, his family feels like the death was premature and unexpected. They wanted more time.



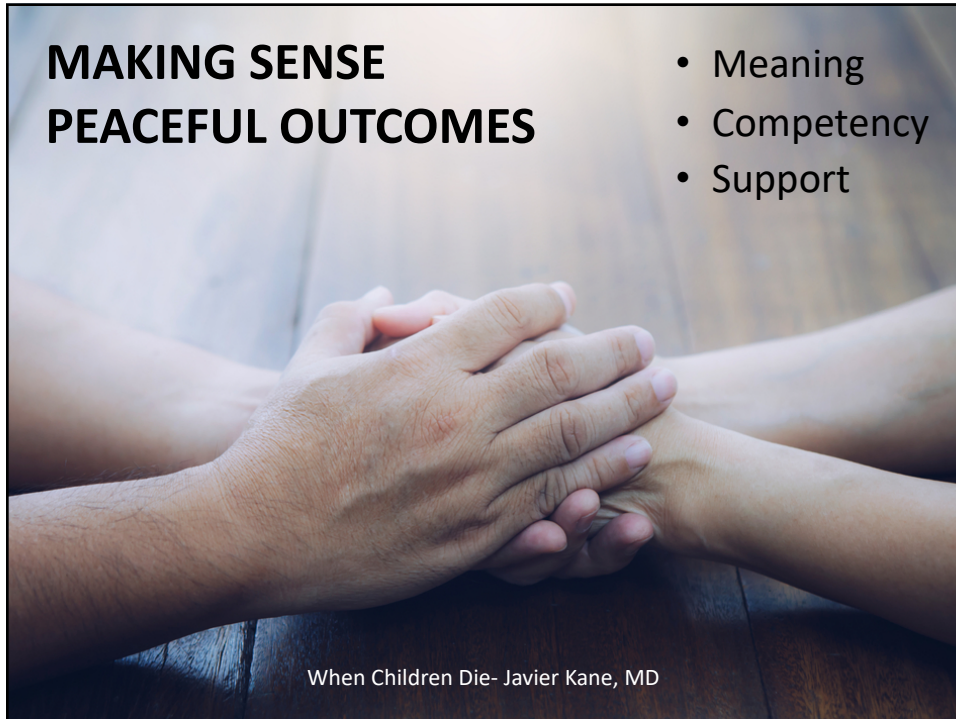
22

A woman with dark hair tied back, wearing a white lace top, is sitting on the floor and talking to a young child. The child is wearing a grey and red t-shirt and is looking at the woman. They are both smiling and appear to be in a close, affectionate relationship. The background is a plain, light-colored wall.

What might the parents need physically/emotionally at this moment?

Share your response in chat.

23



**MAKING SENSE
PEACEFUL OUTCOMES**

- Meaning
- Competency
- Support

When Children Die- Javier Kane, MD

24

*The process does not end.
The ultimate goal is not resolution. . .
Bereavement effects the mourner in
different ways for the rest of their life.
People do not “get over” the experience;
rather they are changed by it.
Part of the change is a transformed but
continuing relationship with the deceased.*

(Klass et. al., 1996)

25




What are some **DO'S** and **DON'TS** when communicating with the *Bereaved*?

Share your response in chat.


26

Communicating with the *Bereaved*

Don'ts 

- Advice
- Cheer-up
- Assume
- Reassure
- Argue
- Minimize

- Ask Non-judgmental Questions
- Validate /empathy
- Support/silence
- Clarify
- Give information
- Use feeling focused statements

Do's 

ELNEC- 2003

27



Monty and Abigail have been receiving services for their daughter, Ari, since she was 12 months old. Her parents have been concerned about her communication. Ari is now 25 months old and the parents just received an unexpected diagnosis of autism.

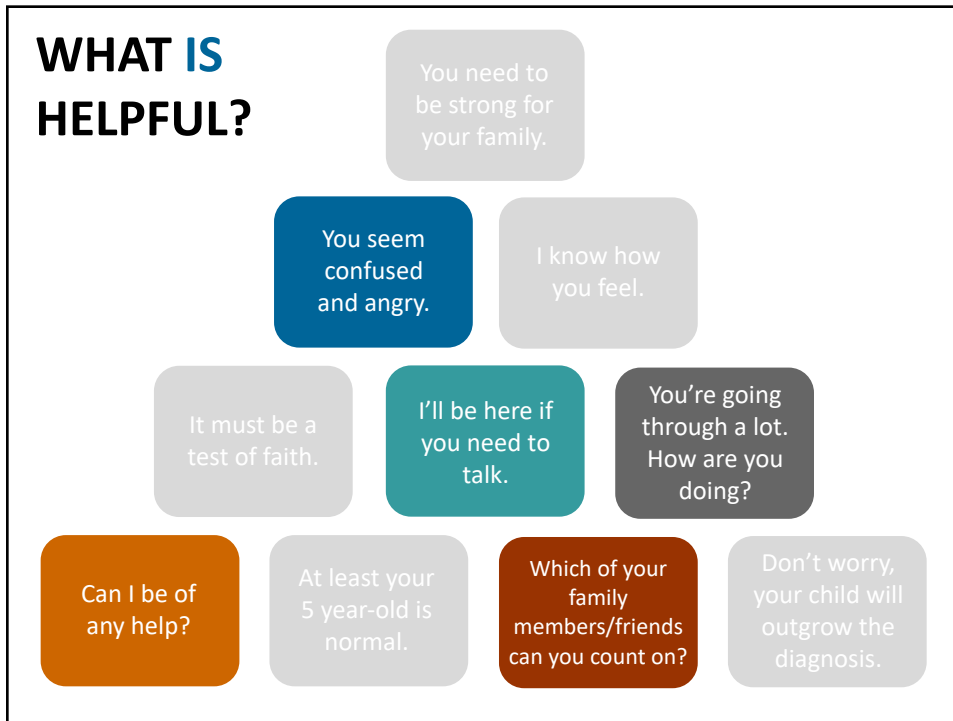
28

WHAT IS NOT HELPFUL?

Use your stamp or drawing tool to make your selections.

- You need to be strong for your family.
- You seem confused and angry.
- I know how you feel.
- It must be a test of faith.
- I'll be here if you need to talk.
- You're going through a lot. How are you doing?
- Can I be of any help?
- At least your 5 year-old is normal.
- Which of your family members/friends can you count on?
- Don't worry, your child will outgrow the diagnosis.

29



30

"In professional training we often learn about the world as though it is a world that we do not inhabit"

Parker Palmer – Courage to Teach

"The doctors and nurses who allowed themselves to show their genuine emotions helped me the most."

Parent of child in the ICU Meyer et al., 2002

31



32

QUESTIONS



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THANK YOU

33