

Companioning Children and Teens When a Loved One is Dying

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Learning Objectives

01

Recognize and identify manifestations of anticipatory grief in children and teens

02

Assess interventions and support for children and teens facing end-of-life situations

03

Describe how secondary losses due to hospitalization and illness influence coping

04

Discuss how limited hospital visitation and changes to end-of-life care during the COVID-19 pandemic are impacting children and families



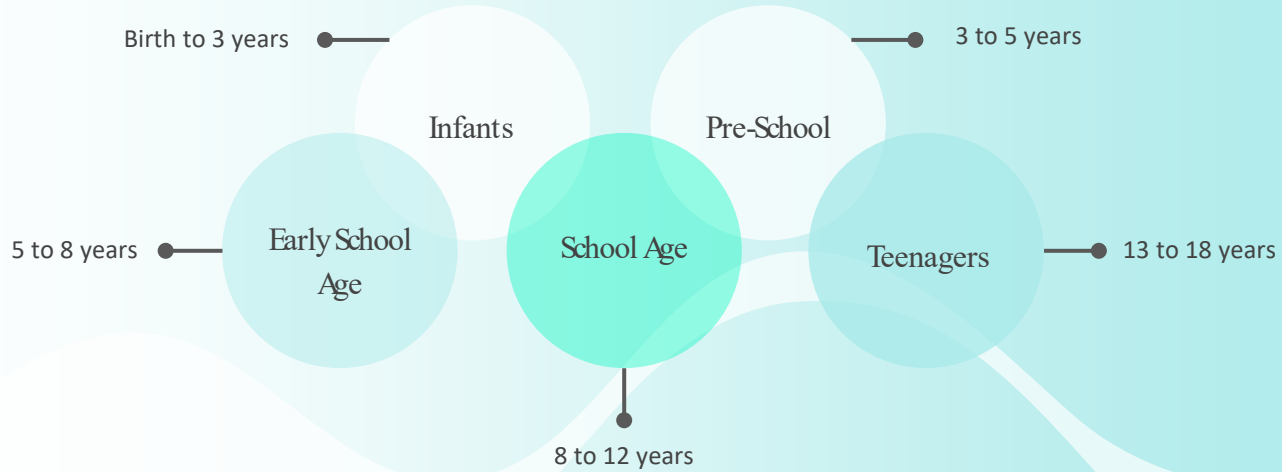
COMPANIONING

“To companion grieving children means to be an active participant in their healing. When you as a caregiver companion grieving children, you allow yourself to learn from their unique experiences. You let them teach you instead of the other way around.”

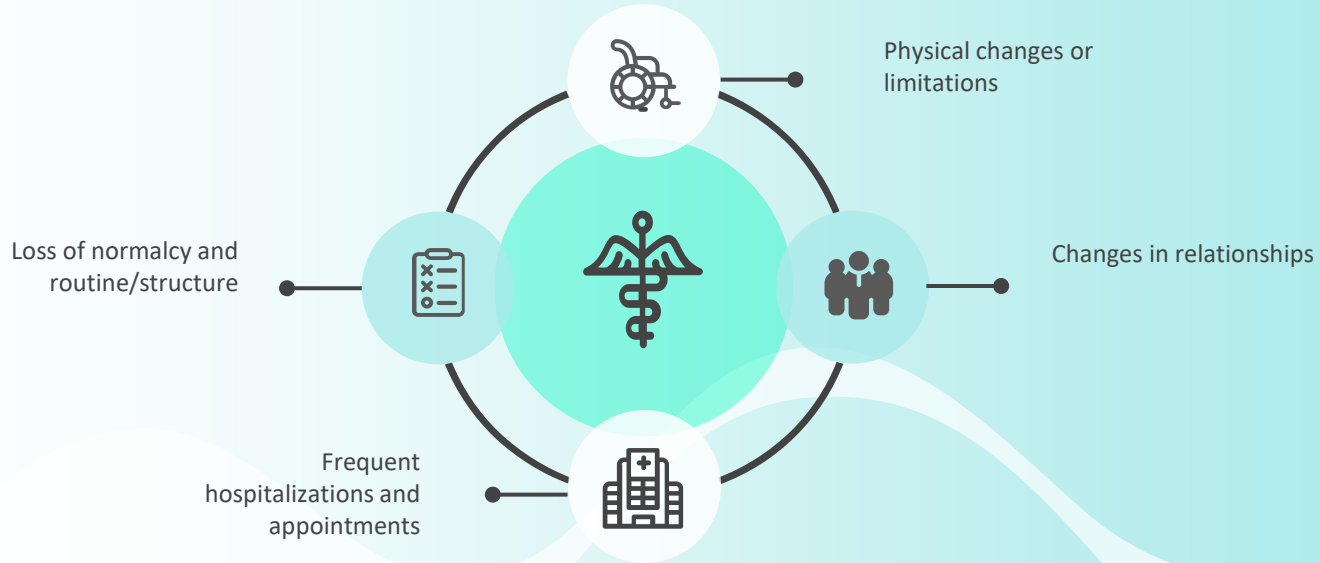
Anticipatory Grief and Research

- Anticipatory grief can be a response to:
 - The anticipated death
 - The loss of function
 - The loss of identity and changes in role
- Includes the mourning, coping, and planning of one's life in response to an anticipated loss
- Not limited to a single experience
- 1 in 14 children experiencing a death-related loss of a parent or sibling before the age of 18 years

Anticipatory Grief by Developmental Level



Secondary Losses Due to Illness

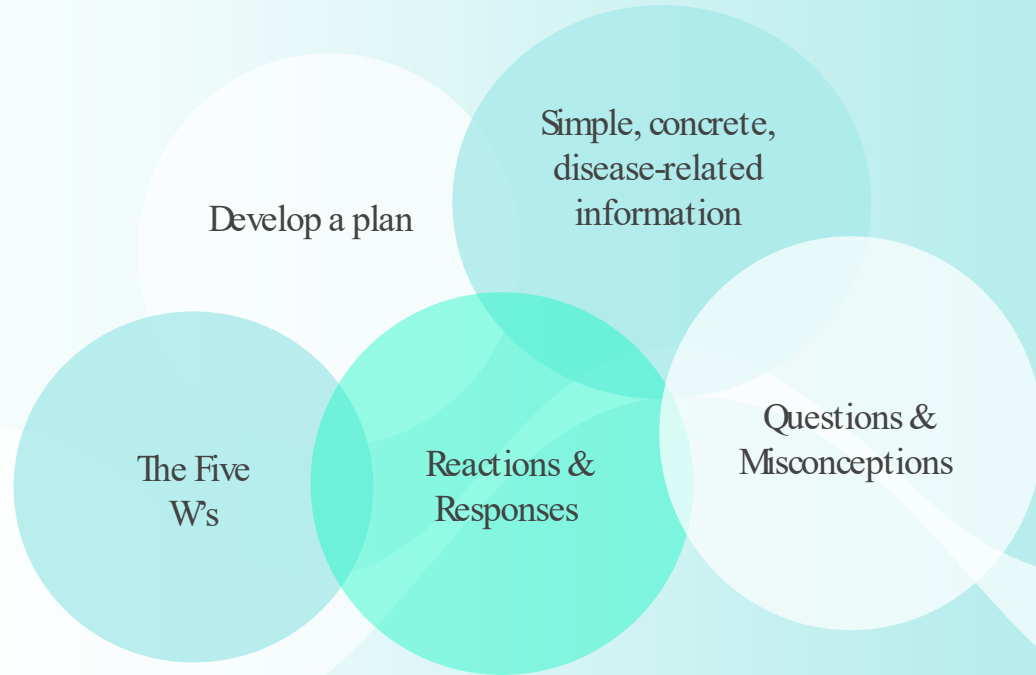


Anticipatory Grief and Communication

- Communication about a serious illness is not a one-time event
- Details shared vary about age and developmental level
- Prior experiences with death
- Cultural and spiritual influences



Sharing Sad News



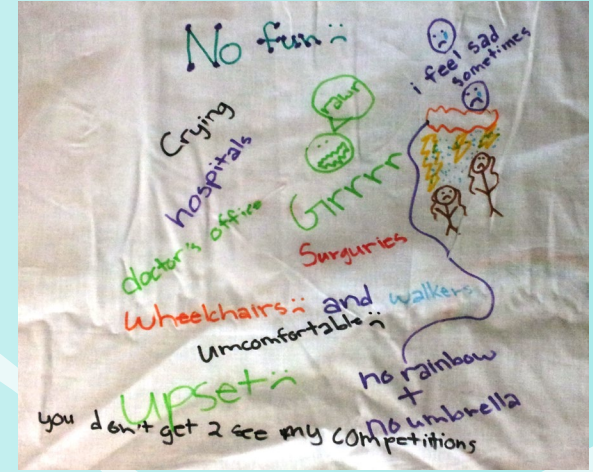
Questions and Misconceptions

- Allowing questions to guide conversation
- 'I don't know' and circling back
- Explanation and preparation for physical and/or behavioral changes



The 5 W's

Why does
god take
good people?
Why did
god make
Cancer?



END OF LIFE VISITS



“Family members and healthcare providers may think that children visiting loved ones in the ICU could be detrimental and that these children do not have the capacity to understand... Conversely, negative behavioral and emotional responses have shown to decrease after visitation.”

OPPORTUNITIES TO SAY GOODBYE



Hospital

ICU, Inpatient Unit, or
Inpatient Hospice



Home

With or without hospice
involvement



Virtual

When visiting is not an option

THERAPEUTIC INTERVENTIONS

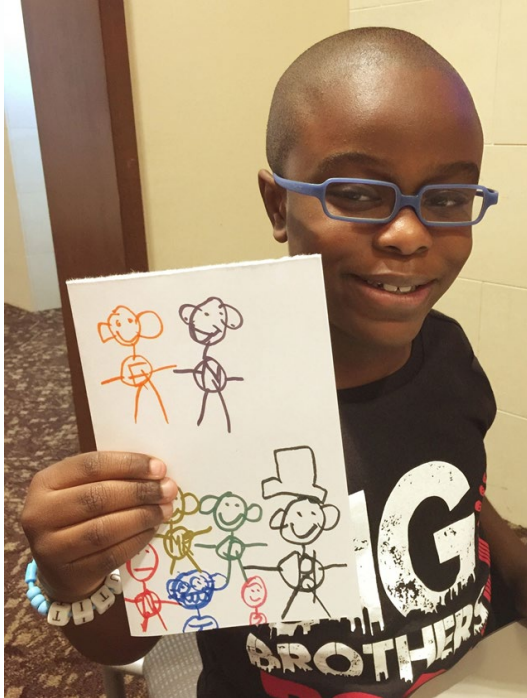


FEELINGS & EMOTIONS

SEPARATION & CONNECTION

LEGACY

Partnering with Families




- Initiating support and advocating for children
- Support at school
- Community Resources



CASE STUDY #1

- 39 year-old mom, Melanie, with cancer who transitioned to home hospice
- Child life support for 10-year-old daughter, Holly
- CLS involved over two years as Melanie's disease progression, hospice transition, and death



38yo male with cystic fibrosis

Wife and 2 children (8, 10)

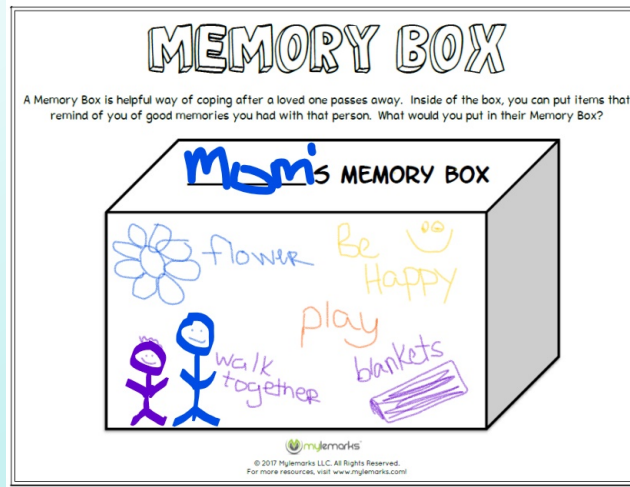
Home and not a transplant candidate

Life expectancy of less than 6 months but not
ready to pursue hospice

CASE STUDY #2

COVID-19

The impact on child life and grief support for children and families



RESOURCES FOR PROVIDERS

How to Help Children Through a Parent's Serious Illness by Kathleen McCue, MA, CCLS

Finding the Words by Alan D. Wolfelt, Ph.D.

Companioning the Grieving Child by Alan D. Wolfelt, Ph.D.

Tool Kit for Educators

<https://www.mghpact.org/assets/media/documents/MGH-Cancer-Educator-Toolkit.pdf>

New York Life Foundation

<https://www.newyorklife.com/foundation/for-school-communities>

Books for Children about Serious Illness

The Cancer That Wouldn't Go Away by Hadassa Field

Someone I Love is Sick by Kathleen McCue

My Daddy's Sick by D. Gonsior

Books for Children about Feelings and Emotions

Color Monster by Anna Llenas

Don't Feed the Worry Bug by Andi Green

In My Heart: A Book of Feelings by Jo Witek

Inside Out: A Box of Mixed Emotions by Disney

The Way I Feel and Other Moods That Make My Day
by Jamie Lee Curtis

Visiting Feelings by Lauren Rubenstein

Books for Children about Death

Everything Changes, but Love Endures: Explaining Hospice to Children by Karen Carney

Something Very Sad Happened by Bonnie Zucker

Badger's Parting Gifts by Susan Varley

Gentle Willow by Joyce Mills

Ida, Always by Caron Levis

What Happened to Daddy's Body? By Elke Barber

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