

Moving Through Grief and Caregiving: Tools and Insights

Presenters:
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Agenda

- Intersections of grief and caregiving
- Different types of grief and loss
 - Anticipatory loss
 - Ambiguous loss
 - Disenfranchised loss
 - Shadowloss
- How to “Speak Grief” better
- How children and adolescents grieve
- Resources!





**There are only four kinds
of people in the world:**

- 1. Those who have been caregivers.**
- 2. Those who are currently caregivers.**
- 3. Those who will be caregivers.**
- 4. Those who will need caregivers.**

Rosalynn Carter
Former First Lady, Activist



We are all survivors of loss.



Understanding the Experience of Loss





Experiences and Symptoms of Grief

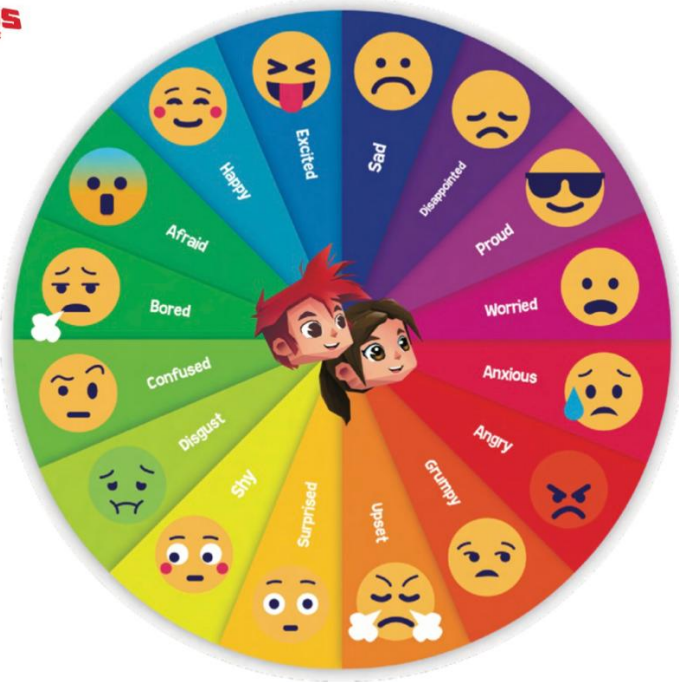
<i>Feelings/Emotions</i>	Physical	Cognitive	Behavior	Social	Spiritual
<ul style="list-style-type: none"> Shock Numbness Sense of unreality Sadness Longing Loneliness Sorrow Self-pity Anguish Guilt Anger Relief Outrage at injustice of the loss Frustration at being unable to control events 	<ul style="list-style-type: none"> Fatigue Tightness in chest/throat hollow stomach Over sensitivity to sound Frequent sighing Shortness of breath Feeling of emptiness in the abdomen Muscle weakness Chills Tremors Insomnia or sleep disruptions Changes in appetite Aimless wandering 	<ul style="list-style-type: none"> Disbelief Confusion Anxiety Depression Sense of disorganization Difficulty making decisions Hallucinations Preoccupation with images of the deceased Paranormal or psychic experiences in which the dead appear or communicate with the living are not unusual 	<ul style="list-style-type: none"> Sleep disturbance Appetite Social withdrawal Need for touch Crying Searching for the deceased Incessant talk about the deceased and circumstances of the death Avoiding talk about loss Irritability Hostility Withdrawal from social interactions Over activity and restlessness 	<ul style="list-style-type: none"> Need for rituals Need for support Marital difficulties Role changes 	<ul style="list-style-type: none"> Reexamination of religious or spiritual beliefs Sources of consolation and comfort in coping Questioning fundamental assumptions Relearning how to live in a world affected by loss





Emotional Wheels

KAIROS
HEROES OF TIME



KAIROS
HEROES OF TIME



KAIROS
HEROES OF TIME



The “Course” of Grief



- Initial phase: Shock, numbness, disbelief, denial
- Middle phase: Anxiety, despair, volatile emotions, yearning for deceased, feelings of abandonment
- Last phase: Sense of resolution, reintegration, and transformation; turmoil subsides; balance regained

“Grief is a typical, expected experience. We will all experience losses in our lives. . . None of us will get out of this life without grieving, and without knowing other grievers.”

– MacDonald, 2024

Factors that may complicate grief...



Sudden, unanticipated death

Loss of a child

Perception that the death was preventable

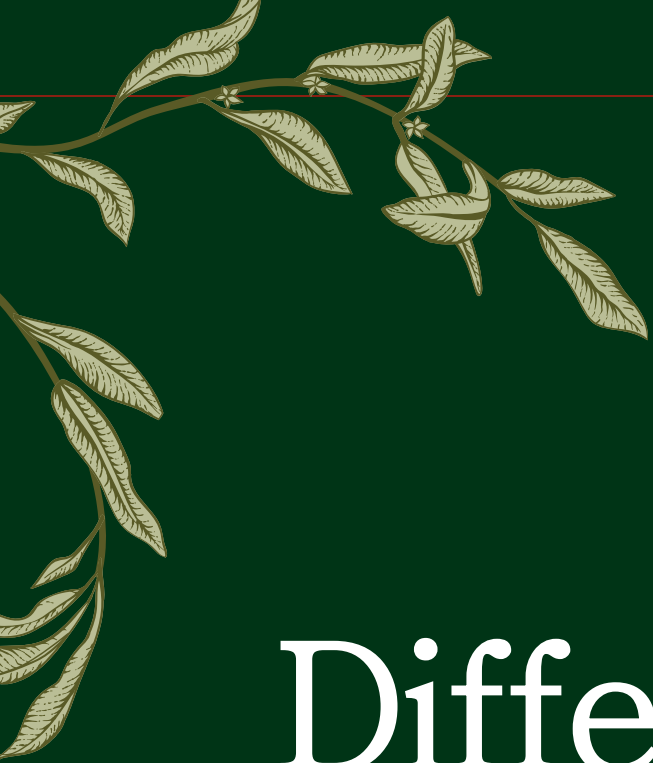
Relationship that was markedly angry, ambivalent, or dependent

Mental health problems or unaccommodated losses

Social processes (e.g., urbanization, acculturation, de-ritualization, violence, availability of guns, random acts of violence, general sense of hopelessness)

Long duration of illness/disease and caregiving responsibilities

Perceived lack of social support



Different Types of Grief & Loss





Anticipatory Loss/Grief

Intense emotional, physical, and cognitive distress experienced *BEFORE* an impending, inevitable loss, such as a loved one's terminal illness

- Mourning, coping with future-oriented sadness, and preparing for life without the person

Potential benefits

- Allows time for "saying goodbye"
- resolving regrets
- clarifying misunderstandings





Ambiguous Loss

Type One:

- Physically Absent, Psychologically Present

Type Two:

- Physically Present, Psychologically Absent

Other Types:

- Infertility, migration, divorce, or losing a home can also cause this type of loss

Symptoms & Emotional Impact:

- Difficulty understanding the situation.
- Long-term, non-terminal sadness.
- Feeling stuck or unable to move on.
- Family roles become ambiguous, leading to conflict and strain, particularly when some members accept the loss while others retain hope

Disenfranchised Grief

- Grief experienced in connection with a loss that is not socially supported or acknowledged through the usual rituals
 - Stigmatized losses (e.g., suicide; overdose; HIV/AIDS)
 - Unrecognized relationships (e.g., death of an ex-spouse; non-blood-related close friend; LGBTQ+ partners)
 - Other losses (e.g., unborn child via miscarriage/abortion; loss of health; job loss)
- When the significance of the loss is not recognized or relationship is not socially sanctioned, the bereft has little or no opportunity to mourn publicly


Shadowloss

A Shadowloss is a loss
IN life, not OF life.
It's a loss of
someTHING, not
someONE.

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Shadowloss



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Source: [TedTalk](#) by Cole Imperi. Shadowloss: Shedding Light on Our Hidden Grief



*We don't "move on"
from grief.*

We move forward with it


Professionals' Experience with Grief and Bereavement

- Professionals are not immune!
 - *…expected to perform through continual exposure to death and loss, often without adequate space and support to acknowledge and process the cumulative and collective grief that accompanies that loss.*



How Children & Adolescents Grieve





Early childhood: regression, magical thinking, guilt over “causing” the death

Middle childhood: anger, health concerns, school problems

Adolescents: engage in more effective behavioral and cognitive coping strategies (help seeking, problem solving, expressing feelings, acceptance)

The Bereaved Child





Death of a Parent

- Likely to be most significant loss
 - Loss of security, nurture, and affection
 - Loss of emotional and psychological support
- Memories, feelings, and actions may be used to construct an “inner representation” to sustain relationship with the deceased parent





Death of a Sibling

- May increase sense of vulnerability to death, especially when siblings are close in age
- May be the loss of a protector or caregiver as well as a playmate
- Mixture of emotions producing guilt and confusion



The background is a dark green color with decorative floral illustrations. In the top left, there are light green leaves and branches. In the top right, there is a small red asterisk. On the right side, there are several flowers: a large pink chrysanthemum, a smaller pink chrysanthemum above it, a stem of small white flowers, and large light green leaves at the bottom right.

Helping Children Cope with Change & Loss



1. Include and Involve the Child
2. Encourage Open, Honest Communication
3. Understand the Child's Perspective
4. Provide Emotional Reassurance and Support
5. Use Developmentally Appropriate Coping Tools

Bibliotherapy (using books as aids in coping) can facilitate discussion and understanding





Camp Courageous



How to Speak the Language of “Grief”



“Speaking Grief”



1. Be OPEN to it.
2. Be AWARE of it.
3. Be AVAILABLE to support them:

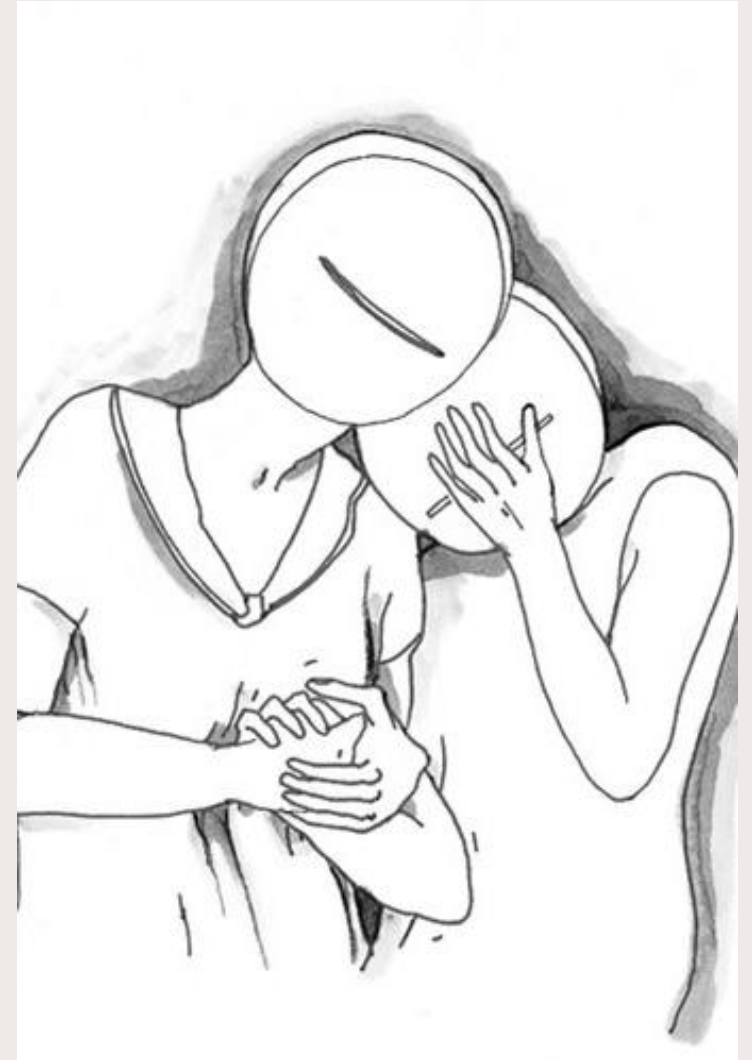
- Being available and open to talk with and listen to them, or hang out, or be a good distraction, or offer some concrete way to make their lives easier.
- Just let them know you're there for them if they want and when they're ready.
- Avoid cliches.
- Don't try to “fix” them or rush their grieving process.
- DO NOT say you understand.
- Check in periodically, though not constantly.

Online Resources



Websites

- <https://modernloss.com>
-
- <https://refugeingrief.com/>
- Griefnet: <http://griefnet.org/resources/index.html>
- Compassion Books: www.compassionbooks.com
- Crisis, Grief, and Healing www.webhealing.com





Grief Out Loud
Episode 350
What If Grief Care
Is Preventative Care?
Dr. Kailey Bradley

LISTEN NOW



Podcast Episode
**What If Grief Care Is Preventative
Care? Dr. Kailey Bradley**
Grief Out Loud



- Sesame Street episode: “When Families Grieve” (~25 minutes)
 - [Pro tip: watch it at 1.25 speed]





- It's Time We Reframe Grief for Children | Kate Atwood | TEDxBigSky

Thank you!

Questions?

Contact Us

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