

Grief Experiences in Pediatric Patients & Families



Megan Schaefer, PhD



NATIONWIDE CHILDREN'S[®]
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Objectives

- **Identify models/theories of grief**
 - **Indicate differences between adaptive and maladaptive grief responses & coping**
 - **Explain the impact of development on a child's understanding of and response to illness and death as well as identify developmentally-appropriate ways to educate and support grieving child**
 - **Discuss grief-focused assessments and interventions for grieving children and families**
-

Definitions

- **Grief:** the anguish, emotional distress, and/or pain experienced after significant loss
- **Anticipatory grief:** the mourning of a loss that not yet happened
- **Disenfranchised grief:** grief that is not openly acknowledged, socially sanctioned, or publicly mourned
- **Bereavement:** the condition of having a loved one die
- **Mourning:** the process of feeling or expressing grief following the death of a loved one

Trajectories of Serious Illness

Diagnosis

**Person may
not survive**

Steady

Remission

**Uncertainty
with scans**



Relapse

**Acute
declines**

**Person is
going to die**

**We are going
to lose our
loved one**



The Childhood Bereavement Estimation Model (CBEM)¹ approximates rates of U.S. children and youth who will experience the death of a parent or sibling by the time they reach adulthood. Results from the CBEM are updated annually using national, state, and regional vital statistics.² Except where noted, this report uses data from 2017 to 2021, the five most recent years of data from the Centers for Disease Control and Prevention.*

Childhood bereavement is a critical issue and an increasingly important national priority. The death of a parent, sibling, or other important person in a child's life is one of the most frequently reported disruptive childhood experiences^{3,4} and without appropriate support, can lead to adverse health and welfare outcomes.⁵ Understanding the number of children impacted by death is essential to help every bereaved child find hope and healing.

1 in 12



children in the U.S. will experience the death of a parent or sibling by age 18

8.3%~6.0M
children will be bereaved by age 18



& MORE THAN **DOUBLES** **14.7M**
youth will be bereaved by age 25

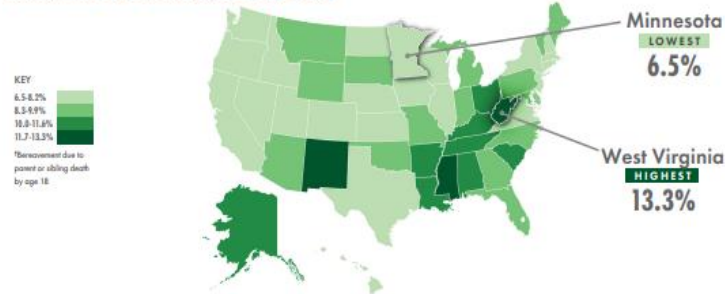
Projected CBEM Results

Projected CBEM results presented above combine estimates of a) the number of children who are already bereaved and b) the number of children who will experience the death of a parent or sibling by ages 18 and 25.

Projected results help individuals and organizations center childhood bereavement as a public priority by:

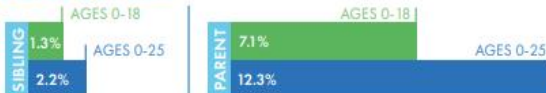
- Forecasting service and systems demands
- Engaging in advocacy and policy efforts
- Building workforce capacity
- Cultivating public awareness and engagement
- Evaluating best practices
- Securing financial support

Childhood Bereavement Rates by State¹



Death of a Sibling & Death of a Parent

The CBEM provides separate, independent estimates for youth who will experience the death of a parent or of a sibling.



© 2023 Judi's House/JAG Institute



National Projected Results 2023

CBEM Leading Cause of Death

The CBEM can produce bereavement estimates by cause of death. Projected CBEM results approximate the number of children under 18 who will be bereaved due to the death of a sibling or the death of a parent by each of the five leading causes of death for youth and adults respectively. Projected CBEM results for death of a sibling and death of a parent are presented below.

Childhood Bereavement by Cause of Death by Age 18

Death of a Sibling[†]

Rank	Sibling Cause of Death	Number of Bereaved Children	Percentage of All Bereaved Children [§]
#1	Birth Conditions	286,000	30.1%
#2	Accidents	148,000	15.6%
#3	Birth Defects	142,000	15.0%
#4	Homicide	47,000	5.0%
#5	Suicide	43,000	4.5%
	All Other Causes	283,000	29.8%
	Total	949,000	100.0%

Death of a Parent^{††}

Rank	Parent Cause of Death	Number of Bereaved Children	Percentage of All Bereaved Children [§]
#1	Accidents	1,685,000	32.4%
#2	Heart Disease	571,000	11.0%
#3	Cancers	550,000	10.6%
#4	Suicide	477,000	9.1%
#5	Homicide	277,000	5.3%
	All Other Causes	1,640,000	31.6%
	Total	5,197,000	100.0%

Sources

1. Bame et al. (2023). *Partner in Pediatrics*, 11.
2. Centers for Disease Control and Prevention. *National Center for Health Statistics, CDC WONDER*
3. Hildrean et al. (2020). *Psychological Trauma: Theory, Research, Practice, and Policy*, 32(1), 119-127.
4. Pynoos et al. (2014). *Psychological Trauma: Theory, Research, Practice, and Policy*, 45(Suppl 1), S9-S17.
5. Beeghin et al. (2017). *BMC Palliative Care*, 16 (39).

*Please see the CBEM Technical Appendix for additional information.

†Sibling results are based on data for those ages 0-17 for 2017-2021.

§The percentage of bereaved children is the quotient from dividing the number of children who will be bereaved due to a specific cause by the total number of children who will be bereaved.

††Adult results are based on data for those ages 27-65 who are most likely to have children 0-18 years old for 2017-2021.



For more info about the CBEM and additional national, state, and local data, visit judishouse.org/CBEM

© 2023 Judi's House/JAG Institute



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Theories/ Models of Grief



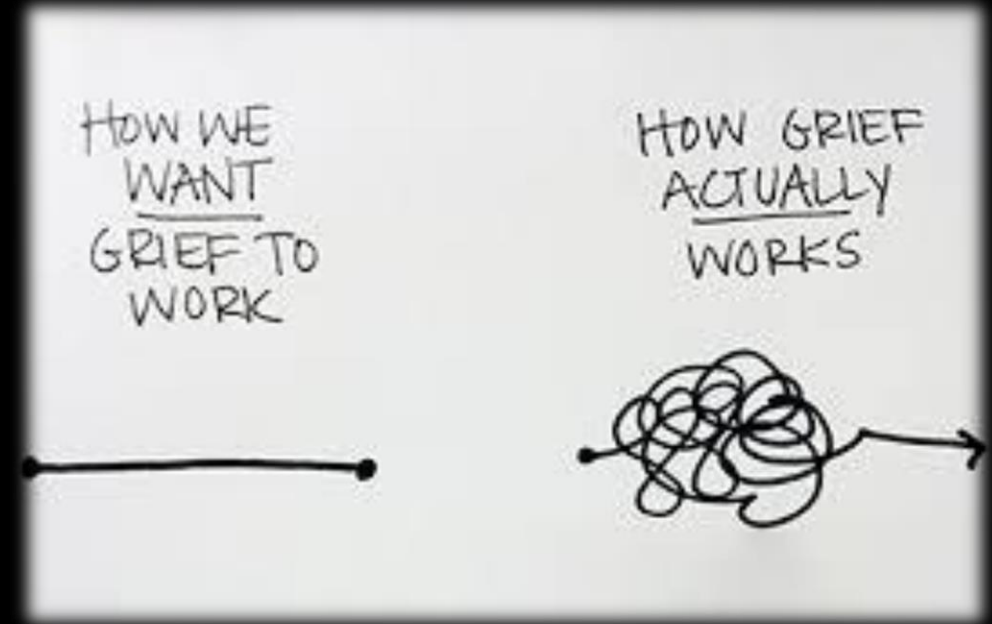
NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



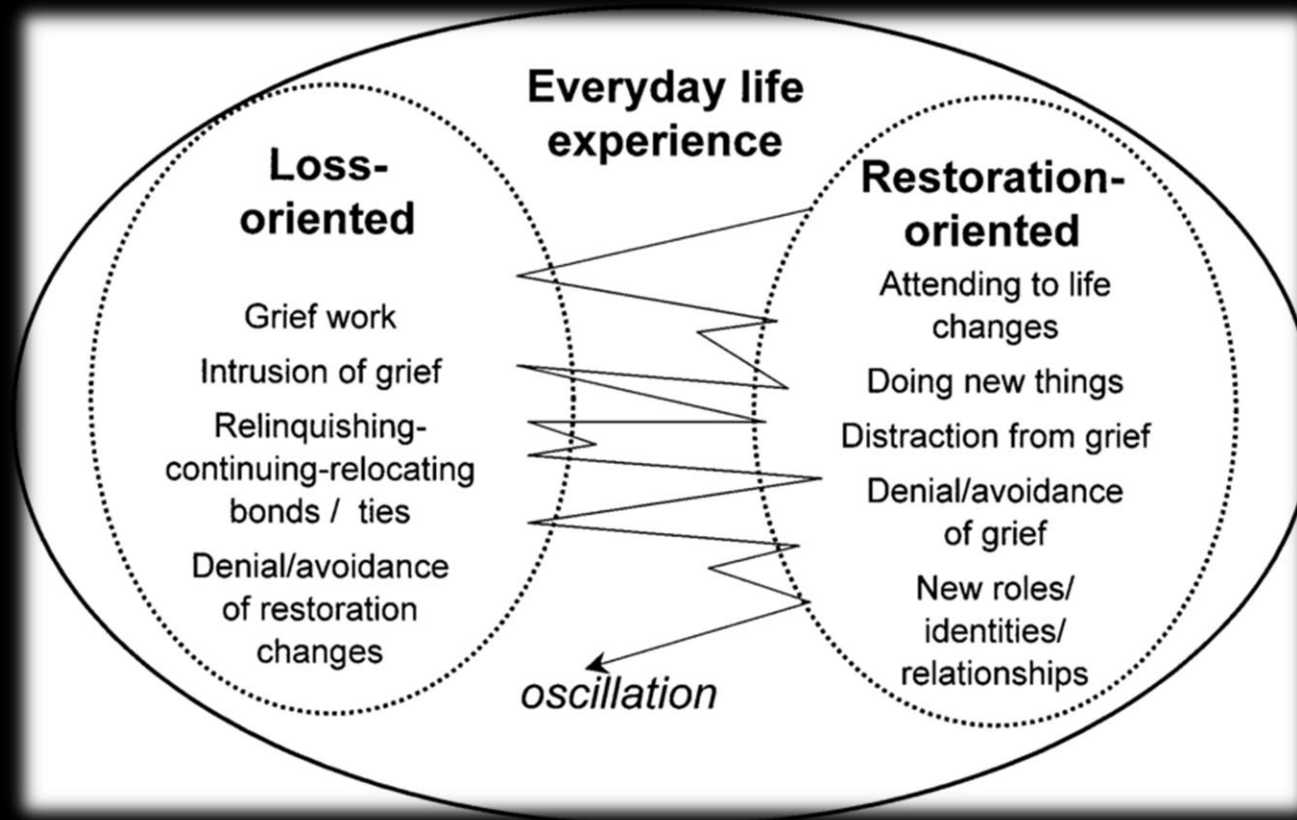
THE OHIO STATE UNIVERSITY

Elizabeth Kubler-Ross 5 Stages of Grief

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

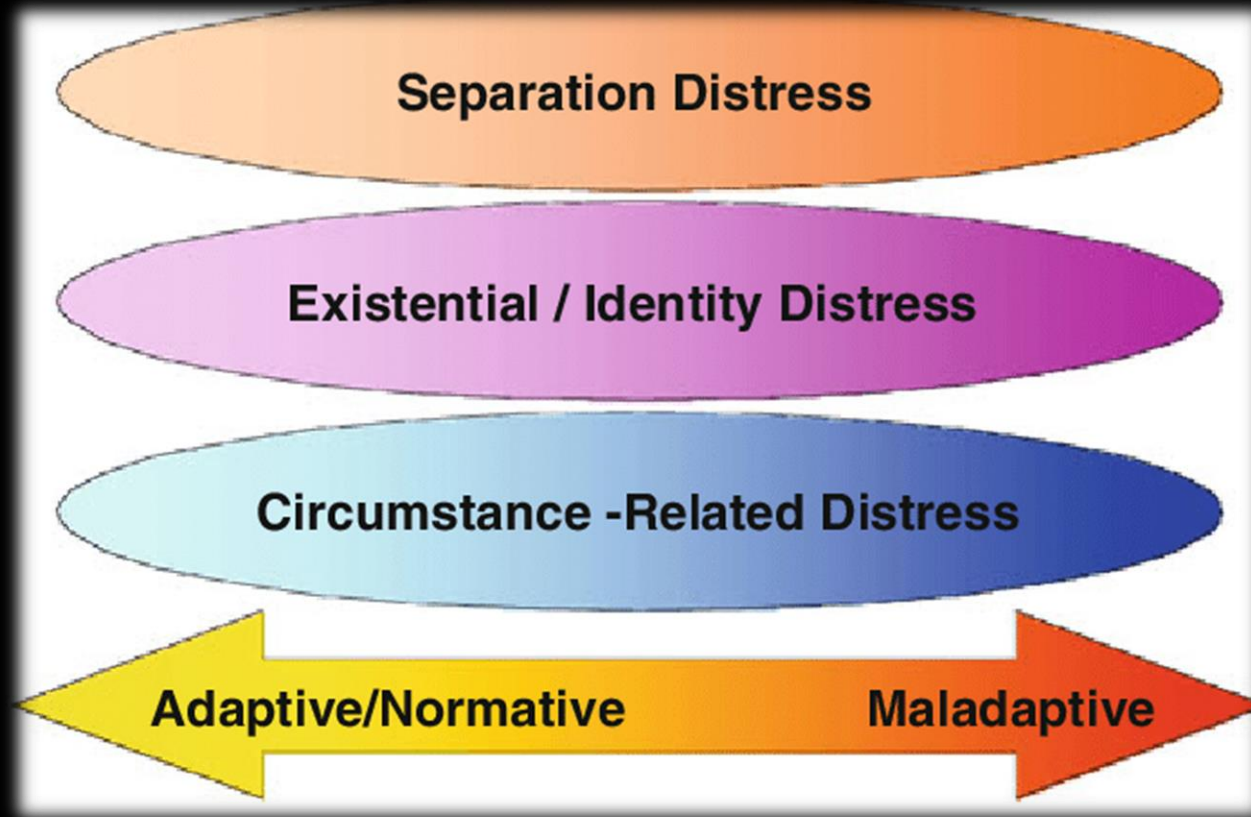


Dual Process Model of Grief



Shutt, 1999

Multidimensional Grief Theory



¹Kaplow et al., 2013

Continuing Bonds



*We don't leave
deceased loved ones
behind. Rather, we
carry them with us
throughout our lives.*

Can you stay close?



Goodnight, Dad. I miss you.



**Yes,
this is
normal.**



Impact of Childhood Grief

- Increased risk for depression, anxiety, sleep difficulties, traumatic stress, guilt, substance use, & low self-esteem
- More vulnerable to social difficulties, lower social competence, & higher social withdrawal
- Linked with physical health in adulthood
- Poorer academic performance
- Post-traumatic stress vs. post-traumatic growth



Adaptive Adjustment to Grief

- Talks openly, asks questions
- Feels comfortable expressing thoughts and feelings related to death
- Balance:
 - Positive & negative events & feelings
 - Focus and process the loss while rebuilding life after loss
- Able to talk about deceased
- Move forward in healthy developmental trajectory



Cultural Considerations

- How people care for the patient as they approach death
- How a person's body is handled after death
- Whether grief is expressed quietly, privately, loudly, publicly
- What rituals they perform after death and who is included in rituals
- How long family grieves
- How the deceased are honored over the lifetime of the family
- What new roles family members are expected to take on



Prolonged Grief

- **Persistent yearning, preoccupation with the deceased, and intense emotional pain that causes significant functional impairment (Prigerson et al., 2009)**
- **Lasts more than 6 months after death (children/adolescents) and 1 year after death (adults)**
- **Expected to apply to around 4% of bereaved people**



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Symptoms of Prolonged Grief

- Longing, yearning for person who died
- Intense feelings of emotional pain, sorrow, or pangs of grief
- Avoid reminders that the person who died is gone
- Felt stunned, shocked, dazed by loss
- Confused about your role in life/don't know who you are
- Troubles accepting the loss
- Feel bitter over the loss
- Believe moving on would be difficult
- Emotionally numb
- Feel that life is unfulfilling, empty, or meaningless



Developmental Considerations



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

4 Basic Concepts about Death

1. Death is irreversible.
2. All life functions end completely at the time of death.
3. Everything that is alive eventually dies.
4. There are physical reasons someone dies.



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Infants



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Concept of Death

- **Development**
 - Learn the world through movements/sensations
 - Pre-conceptual (difficulties grasping concepts)
 - Present oriented
- **Response**
 - Can be seen as abandonment
 - Reversible; not permanent

Grief Reactions

- **More crying**
- **Thumb/finger sucking**
- **Can sense anxiety & sorrow**
- **Increased clinginess**
- **Sleep more and wake more frequently**
- **May be more hyper/energetic**
- **Most aware of altered patterns of care**



Best Ways to Help

- **Keep baby's schedule**
- **Talk to infant as you hold them in calm/soothing tone**
- **Be honest/ answer questions**
- **Let them know they will be taken care of**



Preschoolers



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Concept of Death

- **Development**
 - Gaining autonomy; exploring world
 - Egocentric thinking
 - Language increasing
 - Fantasy thinking and wishing
- **Response**
 - Can still see death as reversible
 - Personification of death
 - Feelings of responsibility

Grief Reactions

- **Irritable**
- **Regressing to an earlier age (bedwetting, thumb-sucking, baby talk)**
- **Showing fear of separation (clingy)**
- **Increased fears/nightmares**
- **Talking about death over and over**
- **Unable to verbalize feelings**
- **Showing little to no concern at times and returning to play**



Best Ways to Help

- **Patience & reassurance**
- **Use straight-forward concrete words to talk about death**
- **Be honest and answer all of child's questions**
- **Set limits for behaviors that are unacceptable**
- **Maintain familiar routines.**
- **Give your child chances to play and draw in relation to death**
- **Read books about death and loss that fit child's age**
- **Model healthy grieving**
- **Give children choice to participate in funeral**

Tips on Language

- Use simple, clear, and honest language with child
 - Use “dead”, “body stopped working”
 - Avoid “passed away,” “gone to sleep,” “taken to a better place”
- May not understand the concept of “forever”
- May believe they did something to cause the death



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Possible Questions

- “What does dead mean?”
- “Is death like going to sleep?”
- “Is he hungry? Is he cold?”
- “Will he come back?”
- “Did I do something bad to cause the death?
Did I think something that caused it?”
- **IT’S OKAY IF YOU DO NOT HAVE ALL OF THE ANSWERS**
 - “That’s a good question. What do you think?”



School-Aged Children



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Concept of Death

- **Development**
 - Concrete thinking
 - Self-confidence is developing
 - Increased socialization
 - Logical thinking
- **Response**
 - Death as punishment
 - Wanting to see death as reversible but understanding permanence
 - Universal

Grief Reactions

- **Anxiety**
- **Crying**
- **Denial**
- **Guilt**
- **Withdrawal**
- **Anger**
- **Drop in grades**
- **Regressions**
- **Acting out**
- **Daydreaming/ difficulties paying attention**
- **Fear of own death or death of caregiver**
- **Somatic symptoms**
- **SI**



Best Ways to Help

- **Tell child it is okay to feel sad, angry, and scared about death**
- **Give child chance to tell the special person things that they may have wanted to say**
- **Allow child to release energy through physical activities**
- **Encourage child to express grief through stories, poems, & music**
- **Foster memories**
- **Opportunity to participate in funeral**



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Understanding Death

- Are in the process of understanding what death means
- May start asking harder question such as “why?”
- May wonder about physical changes of the dead person’s body
- May become fearful of sleep, sickness, or anything else that could lead to death
- Guilt/regret for things they wish they would have done or said before special person died



Possible Questions

- “Why did they die?”
- “Will I die? Will you die?”
- “Does it hurt to die?”



Adolescents



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Concept of Death

- **Development**
 - Formal operational problem solving
 - Abstract thinking
- **Response**
 - Conceptualizes death
 - Tries to make sense of death

Grief Reactions

- **Anxiety**
- **Crying**
- **Denial**
- **Guilt**
- **Withdrawal**
- **Anger**
- **Drop in grades**
- **Risk taking**
- **Sleep issues**
- **Feeling different than peers**
- **Feelings of life being unfair**
- **Increase in conflict**
- **Assume more responsibilities**
- **Search for spirituality**



Best Ways to Help

- **Tell adolescent it is okay to feel sad, angry, and scared about death**
- **Be there for adolescent to talk and process emotions**
- **Create rituals of memory**
- **Relieve adolescent of burden of adult responsibilities if feeling pressure to take on more**
- **Encourage them to seek support from others**
- **Encourage adolescent to share how they can be best supported**



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Attending Funerals

- **Preparation & education**
 - Where will service take place?
 - Who will be there?
 - Will there be music?
 - Describe what people will do at service. Will guests cry/share stories? Serious? Laughter?
 - Will there be a casket? Open?
 - Graveside service?
 - What is my role? How will people respond to me?



Explanations



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Death/Dying

- **“Dying is when the body stops working. When you die, your heart and lungs stop working. When grandpa dies, he will not be able to breathe, eat, sleep, or cuddle with you anymore.”**
- **“Sometimes when people get really old, their body can’t work anymore. Being sick is not the same as dying. There are some illnesses that are more serious like Grandpa’s that can make the body stop working.”**
- **“Our thoughts and feelings come from our brain, and sometimes a person’s brain can get sick too. The sickness can cause a person to feel badly inside. It can make a person’s thoughts get all jumbled and mixed up, so they can’t think clearly. Some people can’t think of any other way of stopping the hurt they feel inside.”**

Back to School with Grief



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Best Ways to Help

- **Ask student what they would like shared with teachers and classmates.**
- **Make a difficult day safety plan**
- **Check in with parents/caregivers/loved ones**
- **Plan drop-off and pick-up routines**
- **Discuss after-school rituals**
- **Address challenges with concentration, memory, and school assignments**
- **Make time for recreation, play, and friends**
- **Children often need help communicating condolence and comfort messages**
- **Help children anticipate potential changes in friends' behavior**

Assessment & Interventions



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Assessments

- **Prolonged Grief Disorder Checklist**
 - [PGD Checklist | Trauma and Grief Center \(qualtrics.com\)](https://www.qualtrics.com)
- **Grief Facilitation Inventory**
- **Intrusive Grief Thoughts Scale**
- **Short Mood and Feelings Questionnaire**
- **PTSD UCLA Questionnaire**

Psychoeducation

- Anticipate grief triggers
- Grief cannot be fixed- only carried
- It is okay to embrace diversion from grief and to experience positive emotions.
- No right way to grieve
- Grief does not have a timeline
- Children do not need to be protected from death
- You can still have a relationship with the deceased

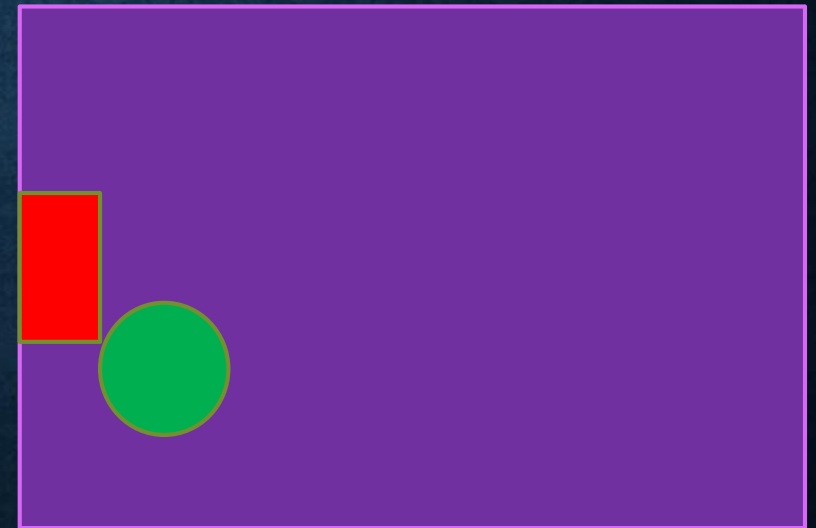
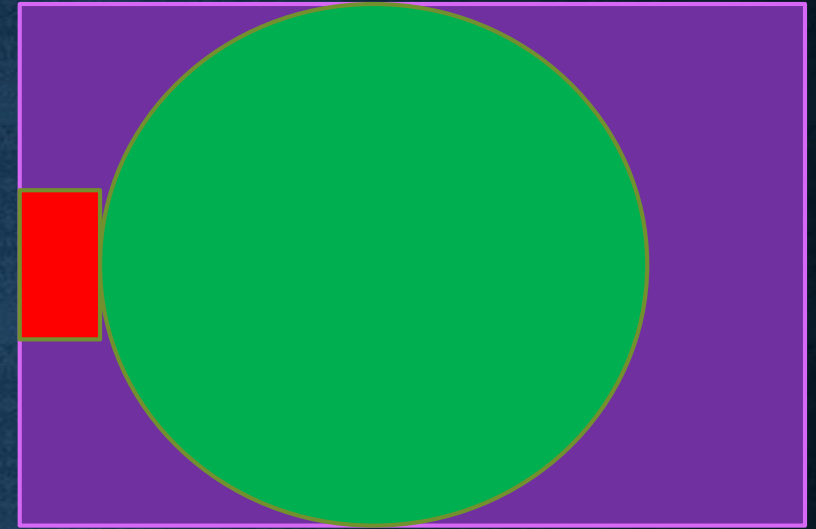




People tend to believe that grief shrinks over time

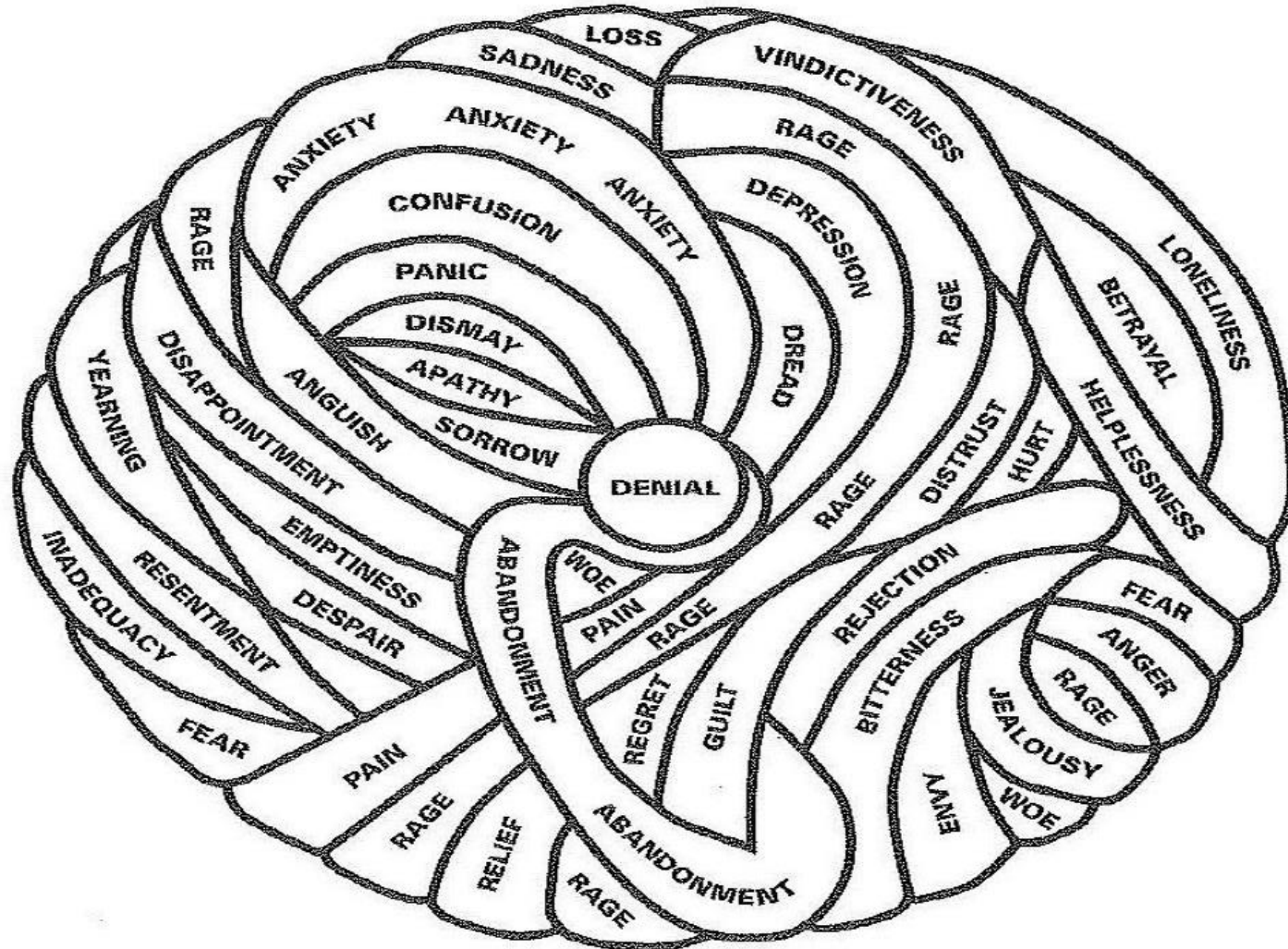


What really happens is that we grow around our grief



BALL OF GRIEF

A TANGLED "BALL" OF EMOTIONS



CARE & FEEDING of YOUR GRIEVING PERSON

@refugeingrief

LEAVE THEM CARE PACKAGES



BE SPECIFIC ABOUT HOW YOU CAN HELP



ASK QUESTIONS



REMEMBER BIG DATES

SET A CALENDAR REMINDER FOR BIRTHDAYS, ANNIVERSARIES, HOLIDAYS AND SEND A TEXT OR NOTE.



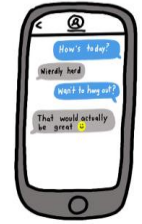
PARALLEL PLAY

YOU DON'T HAVE TO TALK TO SPEND TIME TOGETHER. YOUR PRESENCE MATTERS.



ACKNOWLEDGE THE LITTLE DATES

AN ORDINARY SATURDAY CAN SUCK TOO.



SAY THEIR NAME

SHARE A MEMORY, SAY THEIR PERSON'S NAME.



LET THEM BE SAD

SADNESS IS HEALTHY.



BE AWKWARD

IT'S OK IF YOU DON'T KNOW WHAT TO SAY OR DO. YOUR FRIEND NEEDS YOU! DON'T LET FEELING AWKWARD STOP YOU.



YOU DON'T NEED TO BE PERFECT, JUST PRESENT. 

Focusing on Precious Time Together

- **Make an “I wish I could” list and do activities as person with illness has energy**
- **Have person with illness pick out a gift for someone they love**
- **Record cute/funny things your child says, record songs**
- **Read books**
- **Make scrapbooks**
- **Family art projects**
- **Find opportunities for laughter**
- **Discover new things about each other**



Supporting Siblings

- **Validate & normalize all emotions**
- **Use open and honest language**
- **Explain emotions in family**
- **Include siblings in child's care as desired**
- **Connect to their lives. Special time if possible. Assure them it is okay for them to continue sports & other extracurricular activities.**
- **Find times of joy for family activities**
- **Connect with siblings' school**



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY

Basic Interventions

- **Depression:**
 - Parenting: communication, warmth
 - Behavioral activation
- **PTSD**
 - CBT for childhood traumatic grief
- **Anxiety**
 - Separation, sleep, worries about death/dying
 - CBT ~ exposures, relaxation training, thought challenging
- **Behavior**
 - Positive parenting, maintaining structure/routine, behavior management



Grief- Specific Interventions

- **Family Bereavement Program**
- **TF-CBT for Traumatic Grief**
- **The Grief & Trauma Intervention (GTI)**
- **Trauma and Grief Component Therapy for Adolescents (TGCTA)**
- **Multidimensional Grief Therapy**
- **Meaning-Centered Grief Therapy**

Continuing Bonds

- What do you miss most about them today?
- What is a funny/favorite memory you can think of?
- What do you think they would be doing/saying during this time?
- How would things be different for us if they were here?
- Sharing of stories, video recordings, scrapbooks
- Carry picture, wear special clothing item
- Celebrate their birthdays, include them in continued holiday traditions
- Make a playlist of their favorite music, eat their favorite meal
- Card deck with questions about loved one

Grief Websites



- National Alliance for Children's Grief
- The Dougy Center for Grieving Children & Families
- Courageous Parents Network
- Coalition to Support Grieving Students
- Sesame Street



Grief Books

- **The Goodbye Book**
- **Remembering Blue Fish**
- **The Invisible String**
- **Ida Always**
- **What does Grief feel like?**
- **Always Remember**
- **The Memory Box: A Book about Grief**
- **A Kid's Book about Death**
- **A Kid's Book about Grief**
- **The ABCs of Grief: A Children's Book for all Types of Loss and Grief**
- **The Grief Rock: A Book to Understand Grief and Love**
- **Death is Stupid**
- **Sunflower Promise**
- **Fire in my Heart, Ice in my Veins**



Local Resources

- **Central Ohio Grief Care Coalition**

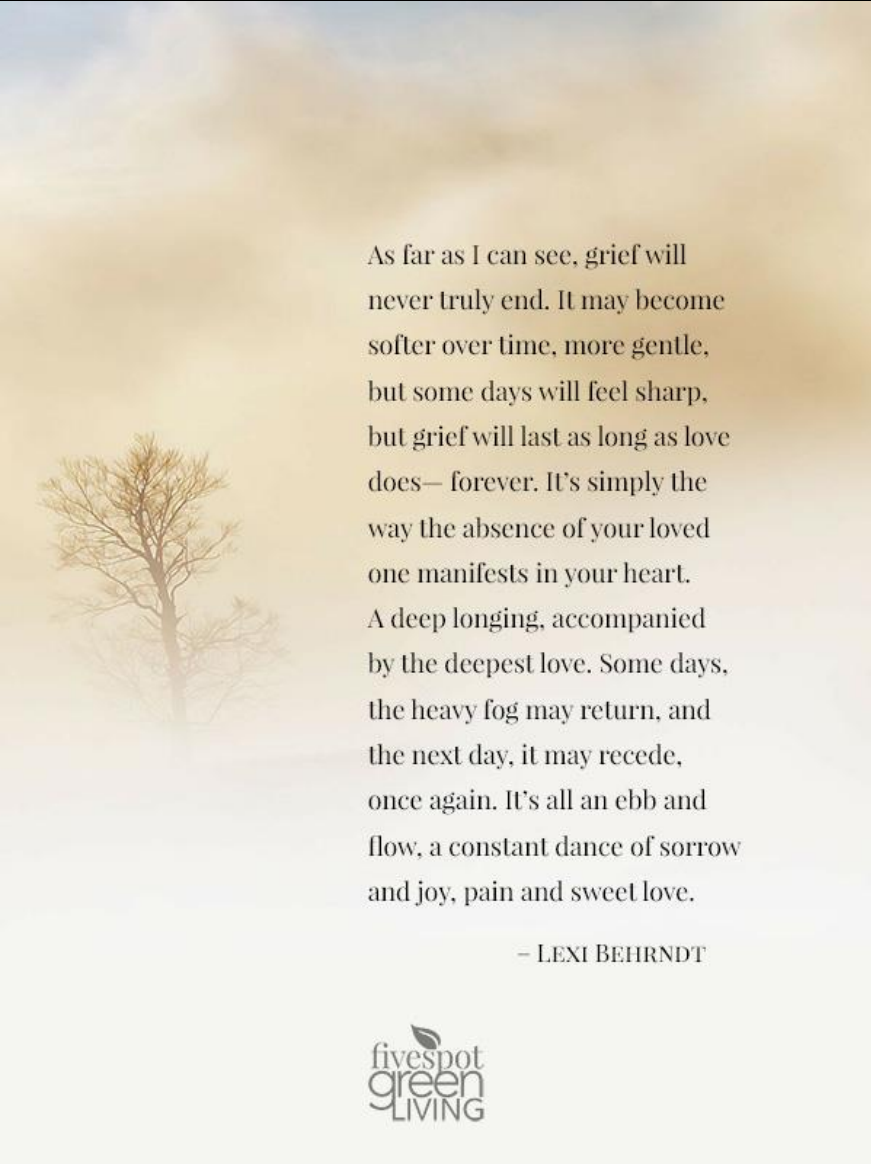
- Ohio Health (individual counseling, grief groups, school supports, art therapy, memorial events)
- Cornerstone of Hope (individual counseling, support groups, in-school groups, annual memorial events, summer camps)
- Hospice
- Camp Lionheart
- Camp Kesem (tOSU)- children with parents with cancer
- Flying Horse Farms Camp

- **Bereavement and End-of-Life Anchor page**

- **.bereavementresources** smart-phrase on EPIC



Questions?



As far as I can see, grief will never truly end. It may become softer over time, more gentle, but some days will feel sharp, but grief will last as long as love does— forever. It's simply the way the absence of your loved one manifests in your heart. A deep longing, accompanied by the deepest love. Some days, the heavy fog may return, and the next day, it may recede, once again. It's all an ebb and flow, a constant dance of sorrow and joy, pain and sweet love.

– LEXI BEHRNDT



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.



THE OHIO STATE UNIVERSITY