“Supporting Your Pediatric Patients and Their Families Through Experiences of Grief and Loss”

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New Jersey Department of Children and Families

Hackensack Meridian Health

Cooper University Health Care

The Children’s Hospital at Saint Peter’s University Hospital
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Atlantic Health System
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New Jersey Chapter
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American Academy of Pediatrics
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There Are No Disclosures
Learning Objectives:

1. Describe the various events that can cause grief and loss in a child’s life.
2. Understand the core philosophy and stages of grief.
3. Understand the different ages and stages youth can be affected by and respond to grief and loss.
4. Identify the warning signs, as well as best ways to screen and identify any mental/behavioral problems associated with the effects of grief and loss in your pediatric patients.
5. Discuss effective strategies for communicating and fostering relationships with your patients and their families during experiences of grief and loss.
6. Identify various resources available to support your patients and their families during experiences of grief and loss.
What is Grief?

What is the “goal” or “purpose” of grief?
• Grief is a multifaceted response to loss
• Grief is a compilation of emotions and more
  ◦ Emotional, intellectual, spiritual, and physical
Grief is a good, healthy response to loss
  ◦ It enacts a series of responses that help individuals to rebuild after loss.
Prevalence of Childhood Bereavement

• An estimated **1 out of 7** children in the U.S. will experience the death of a parent or sibling before they reach the age of 25.

• **Over 4.8 million youth** are bereaved by the age of 18, and the number nearly **triples by age 25, to 12.7 million**.

• Childhood bereavement is a prevalent and critical public health issue that can have a profound impact on future wellbeing.

Source: Judi’s House J A G Institute  [https://www.judishouse.org/cbem](https://www.judishouse.org/cbem)
The Landscape of Loss & Adversity

- Abuse
- Broken Relationships or Divorce
- Safety, Security, Innocence
- Incarceration
- Poverty
- Family Separation
- Addiction
- Loss of Home or Moving
- Physical & Mental Health
- Domestic Violence
- Death
- Neglect
- Bullying

Source: Adverse Childhood Experiences, Center for Disease Control and Prevention
Potential Risk Factors

Physical Health
- Obesity
- Diabetes
- Heart Disease
- Increased Mortality Risk

Learning & Growth
- Developmental Delays
- Cognitive Function
- Poor Performance in School

Mental Health
- Chronic Stress
- Anxiety & Depression
- Addiction
- Suicidal Ideation

Source: Adverse Childhood Experiences, Center for Disease Control and Prevention
There is Good News!

Research tells us that if we surround this child with supporting relationships and teach her adaptive life skills, these risk factors can be eliminated.

Source: Harvard Center on the Developing Child
A nation-wide survey by The New York Life Foundation revealed that a majority reported it takes as many as 6 years to move forward after experiencing loss, but that support from family and friends wanes within 3 months.

Over Time, Support Fades
Elisabeth Kübler-Ross: The Five Stages of Grief
3 Grief Processes

1. Thinking
   • To understand the reality and the permanence of the loss.

2. Feeling
   • To be allowed to feel all the feelings of grief without judgement.

3. Living & Loving
   • Reinvesting in relationships and the future.
Bereavement & Grief

Bereavement:
• The fact and condition of the loss; period after a loss during which grief is experienced and mourning occurs.

Grief:
• The process of reacting to loss; emotional, cognitive, functional and behavioral responses.
Uncomplicated Bereavement

- Reconciliation
- Acknowledge the reality
- Identify and Express the emotions
- Adjusting to life without a loved one or the prior condition
- Finding meaning in the loss of loved one
- Becoming engaged with others
Grief Responses

Normal grief response:
• Sadness, Crying
• Withdrawal or lack of interest in normal activities
• Loss of Appetite or sleep problems
• Decline in academic performance
• Longing for the deceased

Abnormal grief response:
• Excessive and prolonged adverse responses to physical, emotional, behavioral, academic and social symptoms
Signs of Abnormal Grief Responses

**Physical symptoms** – headaches, stomach pains/nausea, sleep disturbance, eating issues, frequent accidents or injuries

**Academic problems** - Loss of focus, inattention, doing poorly in school and/or refusal to attend school

**Emotional** - depression, overly sensitive, apathy, low energy, hopelessness, anxiety and new fears – fears of getting ill themselves, preoccupied with death and dying

**Social** – withdrawal from friends, changes in relationships, use of substances

**Behavioral** - Risk taking and high need for attention, clinging, social isolation, aggression

- These can take weeks to months to manifest
Child’s Experience of Grief

For many children, death and grief are the first awareness of their own vulnerability –

Children may feel:
• They are not in control
• The world is pointless
• They themselves are not worthy
# Child Development and Grief

<table>
<thead>
<tr>
<th>AGE</th>
<th>UNDERSTANDING</th>
<th>BEHAVIORS</th>
<th>NEEDS</th>
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<tbody>
<tr>
<td>0-2</td>
<td>• Can sense something is different. • Will not be able to understand the change. • Will likely not have memories of the deceased.</td>
<td>• Fussiness/clinging • Regressive behaviors</td>
<td>• Non-verbal love and care • Stable routines</td>
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<td></td>
<td>• Often conceive of death as temporary and believe the person will return. • Fear of separation, not death itself. • Difficulty understanding heaven, the afterlife, etc. • Will seek a substitute for attachment with the deceased. • Memories may fade over time.</td>
<td>• Developmental regressions • Fear of separation • Nightmares • Behavioral shifts such as aggression or withdrawal</td>
<td>• Stable routine • Honesty • Answers to questions • Love and reassurance of safety</td>
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<tr>
<td>6-9</td>
<td>• Will more quickly grasp the permanence of death. • Can develop fear of death and others they care about dying (parent, friend, teacher). • May feel guilt and conceive of death as punishment for behavior. • Magical thinking: “I am the cause of death.”</td>
<td>• Developmental regressions • Grief ebbs and flows • Behavioral shifts such as aggression or withdrawal • Somatic complaints</td>
<td>• Stable routine • Honesty • Safe modes of expression • Answers to questions • Validation of feelings</td>
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## Child Development and Grief (cont’d)

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| 10-12 | • Will have realistic view of death.  
• Will want to know details about death.  
• Often identify strongly with the deceased.  
• Will notice more when parents are struggling afterward and hold back from sharing own struggles as a result. | • Blame of self or others  
• Separation anxiety  
• Difficulty concentrating  
• Anger, despair                                                                                           | • Stable routine  
• Agency/choice  
• Validation of thoughts and emotions                                            |
| 13-18 | • Recognize fragility of life.  
• May worry about own death.  
• Recognize and hold on to ways that parents or caregivers are not helpful.  
• Identify with meaning-making narratives.                                                                 | • Aggression, anger  
• Withdrawal  
• Under/over eating and sleeping  
• Increased risk-taking  
• Increased drug/alcohol use  
• Self-harming behaviors  
• Somatic complaints                                                               | • Stable routine  
• Honesty  
• Trusted adult/caregiver to listen  
• Present, responsive parenting  
• Agency/choice  
• Validation                                                                                      |
How the Pediatrician Can Help

• Be open, honest and empathic
• Check-in on how your patient is doing and acknowledge the changes occurring in the family
• Allow your patient the choice of going to the wake, funeral – go through the expectations of what will happen
• Help younger children understand what death means
How the Pediatrician Can Help *(cont’d)*

• Discuss the need for structure and routines
• Encourage the child’s need to talk and repeat
• No euphemisms
• Focus on protective factors
Protective Factors: Coping with Loss

1. Parental/caregiver support
2. Healthy diet
3. Sleep
4. Physical activity/exercise
5. Social supports: Break down social isolation
   • Support groups, community agencies, faith community, school, close family, others.
6. Writing, drawing, music, other expressive outlet
7. Mindfulness or meditation practices
8. Nature: Get outside!
Talking with a Family After Loss

• Acknowledge and invite:
  • “I know that your dad died recently. I am so sorry that happened. I want you to know that I am a safe person that you can talk to.”
  • “It’s important for me to bring it up, because I want to make sure we keep you healthy through this. So I am going to ask you a few questions if that is okay?”

• Ask about coping responses

• Ask the parent questions:
  • Do you have any concerns about your child? Have you seen any major behavioral shifts that have you worried?
  • Are you getting support? Communicate the importance of parental self-care.
  • Does your child have someone they can talk to?

• Focus on flagging potential unhealthy coping:
  • Remember, grief is not a pathology. The primary concern is around unhealthy coping responses to the loss.
Warning Signs – Know When to Get Additional Help

Changes to healthy habits
- Lack of or excessive sleep, appetite; significant shifts

Developmental regressions/to previous stage of competency
- Bed-wetting, thumb sucking

Self Harm/Suicide ideation
- Past attempt or expressed intent in the future

Prolonged depression or anxiety
- Overwhelming hopelessness

Signs of childhood trauma
- Heightened fear, terror

Use of Drugs or Alcohol or Risk taking Behavior
Pediatric Psychiatry Collaborative

Regional Hubs

- Atlantic Health Hub @ Newton Medical Center
- Atlantic Health Hub @ Goryeb Children’s Hospital
- Hackensack Meridian Hub @ Hackensack University Medical Center
- Hackensack Meridian Hub @ Palisades Center
- Hackensack Meridian Hub @ Saint Peter’s Family Health Center
- Hackensack Meridian Hub @ Jersey Shore University Medical Center
- Cooper Hub @ Cooper University Medical Center
- Cooper Hub @ Pennsville

Essex County served by Rutgers University Behavioral Health Care.

More information on the Essex Hub can be found here: [https://ubhc.rutgers.edu/clinical/community/collaborative-behavioral-health-care-project-essex-hub/collaborative-behavioral-health-care-project-essex-hub/]
PPC Hub Benefits

- A child and adolescent psychiatrist available for consultative support through the Child Psych. consult line
- A psychologist/social worker available to:
  - Assist the pediatrician with diagnostic clarification and medication consultation,
  - Speak with a referred child’s family regarding the child’s mental health concerns and to assist in providing diagnostic clarification.
- One-time evaluation by a child and adolescent psychiatrist (CAP) at no charge to the patient when appropriate.
- Based on the recommendation of the CAP, the PPC Hub staff will work with the family to develop the treatment and care coordination plan.
- Continuous education opportunities in care management and treatment in the primary care office for the common child mental health issues: ADHD, depression, anxiety, etc.
Children’s Books Recommended by the PPC Hub Teams

• Help Me Say Goodbye, Janis Silverman
• The Invisible String, Patrice Karst
• The Memory Box, Joanna Rowland
• I Miss You, Pat Thomas
Learn more about us!
WWW.GOOD-GRIEF.ORG

Good Grief Stats

- 897 participants, 376 families in peer support programs.
  - 567 children, 330 adults
- 1,200 students reached through Routes to Resilience
- Over 1,600 professionals, parents, and other members of the community received education.
- 161 communities served, 4,000 square miles!
- 250 volunteers make it possible!
- 1,589 pizza’s eaten!
Books and Resources found at
www.good-grief.org
Tips for Teaching Children Emotional Intelligence

• Help children define feelings
• Explore different types of feelings
• Discuss where you can feel emotions in the body
• Identify Helpful and Unhelpful ways to express feelings

Source: Good Grief
What to Expect from Good Grief

To enroll in Family Support Services you must:

• Have experienced the death of a parent, guardian (or other primary caregiver), sibling, or child
• Ages 3-30 and primary caregiver(s)
• Community-based peer support model with groups that meet bi-weekly
• Family Support Services are free and unlimited
• Focused on peer support and skill-building

Source: Good Grief
Alternative forms of therapy and/or interventions to help with Grief and Loss

- Play
- Sand
- Art/Music
- Narrative/story telling and/or writing
- Meditation and mindfulness
- Children’s books/literature
- Parent education

Source: Good Grief
More Suggested Resources

Traumatic Loss Coalition (TLC):

- An interactive statewide program offers collaboration and support to professionals working with school-age youth. The dual mission of the TLC is excellence in suicide prevention and trauma response assistance.

https://ubhc.rutgers.edu/education/trauma-loss-coalition/overview.xml

Imagine, A Center for Coping with Loss:

https://www.imaginenj.org/

• National Alliance for Grieving Children:
  https://childrengrieve.org/resources

• Online forum/social media for teens who lost a parent: https://slapd.com/

• To learn more about the grieving process and to share as well: http://www.hellogrief.org/

• Online “groups”, which are available 24/7: http://www.kidsaid.com/k2k_support.html
Questions for NJAAP?

Please contact:
The Mental Health Collaborative
609-842-0014
mhc@njaap.org

To Register to Participate:
http://njaap.org/programs/mental-health/ppc