

Supporting Siblings

ISSUE #68 | AUGUST 2022



Pediatric E-Journal

PEDIATRIC ADVISORY COUNCIL

Released in collaboration with the National Hospice and Palliative Care Organization



NHPCO

National Hospice and Palliative
Care Organization

Pediatric e-Journal

Pediatric Palliative and Hospice Care

Issue #68 | August 2022

Issue Topic: Supporting Siblings

Welcome to the 68th issue of our Pediatric e-Journal. At one point in time, it was common to say that brothers and sisters of a parent or sibling who was ill or who had died were “forgotten grievers.” In 1992, Magination Press, the children’s book publishing arm of the American Psychological Association, even published a book entitled, *What about Me? When Brothers and Sisters Get Sick*.

It may still be true in many ways or places, that the challenges facing siblings may be ignored or undervalued, but we think it likely that readers of this e-Journal know better than to behave in those ways. We also believe that our readers are interested in learning more about why we should pay attention to supporting grieving siblings and about effective ways of doing so. That is what led us to develop this issue on these subjects.

As you will see from the contributions we received, supporting siblings can mean many different things in many different situations. In this issue, we are happy to share personal stories, experiences taken from bereavement support groups, and reports from pediatric hospice and palliative care professionals who are engaged in the important work of supporting grieving siblings. We do not expect that a single issue will cover every possible aspect of this topic, but we hope to stimulate discussion on at least some of its major dimensions—and perhaps also to bring to readers’ attention some of its lesser-known aspects.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Hospice and Palliative Care Organization. The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Suzanne Toce. Chuck Corr is our Senior Editor. Archived issues of this publication are available at www.nhpco.org/pediatrics.

Comments about the activities of NHPCO’s Pediatric Advisory Council, its e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are currently discussing topics like pediatric hospice and palliative care in the community, perinatal and neonatal hospice and palliative care, and standards for the issues immediately before us. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy Torkildson at christytork@gmail.com or Suzanne Toce at tocess@gmail.com.

Views expressed in this and other issues of the Pediatric e-Journal are exclusively those of the authors and do not necessarily reflect the views of the Pediatric e-Journal Workgroup, the NHPCO Pediatric Council, or the National Hospice and Palliative Care Organization.

Produced by the Pediatric e-Journal Workgroup

Charles A. Corr, PhD, Lacey, WA; Senior Editor

Kathy Davis, PhD, MSED, Retired Professor of Pediatrics, University of Kansas Medical Center, Shawnee, KS

Ann Fitzsimons, BS, MBA, Executive Director, here4U, Inc., Farmington Hills, MI

Michelle Goldbach, Director of Nursing, The Bernardy Center, Rady Children's Hospital, San Diego, CA

Betsy Hawley, MA, Executive Director, Pediatric Palliative Care Coalition, Pittsburgh, PA

Melissa Hunt, PharmD, Pediatric Clinical Pharmacist, Optum Hospice Pharmacy Services, O'Fallon, MO

Nathan Ionascu, MD, Bioethics Consultant, Westchester End-of-Life Coalition, Westchester County, NY

Oralea Marquardt, LCSW, Licensed Clinical Social Worker, Treasure Coast Hospice, Fort Pierce, FL

Jessica Sturgeon, MT-BC, Music Therapist, Seasons Hospice and Palliative Care, Middlebury, CT

Suzanne Toce, MD, Retired Neonatologist, Gundersen Health System, La Crosse, WI; Co-Chair

Christy Torkildson, RN, PHN, PhD, FPCN, Lead, MSN-Public Health Nursing Program, College of Nursing and Health Care Professions, Grand Canyon University, Phoenix, AZ; Co-Chair

Table of Contents

Click on the "bookmark" tab on the left-hand side of the PDF document for links to the following articles.

Issue #68 | Supporting Siblings

Band of Brothers Bound by Grief

Ann Fitzsimons, BS, MBA

1

Three young brothers bereaved first by the death of their baby sister and then by the death of their mother are the central figures in the story of this family as told by a member of our Pediatric e-Journal workgroup. We see examples of the support these boys did not receive and, over a period of many years, some implications of that deficit.

Mourning the Sister I Never Knew

Donna Lynne Schuurman, Ed.D., FT

4

In this poignant personal story, the long-time Executive Director and now Senior Director of Advocacy and Training at Dougy Center tells of the birth and death five days later of her parents' first child. Donna never knew much about her older sister's short life because, "There was an unspoken covenant that it was not to be discussed." When Donna finally asked her mother about this older sibling, she learned that her mother had "carried this burden of guilt and pain for 60 years." And when, after her parents' divorce was finalized, Donna asked her mother when she knew her marriage was over, the reply was, "I knew our marriage was over when I came home from the hospital without the baby, and we could never talk about it."

Unique Attributes of Sibling Grief: "People Look at Me with a Dead Brother Face"

Amy Benner LaBelle, MSW

7

Annie's Hope is a well-established, independent children's grief support program in St. Louis, MO. In this article, the author briefly mentions the sudden, unexpected death of one of her brothers, while focusing primarily on examples and lessons from some of the many bereaved siblings served by Annie's Hope.

Don't Forget Us! Voices of Youth after the Death of a Sibling

Donna L. Schuurman, Ed.D., FT, Monique B. Mitchell, Ph.D., FT, & Alysha Lacey, M.A., FT

10

This article briefly describes the history of Dougy Center's efforts to provide grief support to children, teens, young adults, and their family members. However, the primary focus of the article is on themes youth have shared after the death of a sibling: *I feel like I lost my parent or parents when my sibling died; Now I have to be the 'perfect' kid; My parent/parents are now super over-protective of me; I have had to grow up faster than my friends and I feel like I lost part of my childhood; Identity issues: My only sibling died...am I still a _____?; I'm afraid everyone around me will die. Including myself; I wonder if they ever wish it were me who died instead of my sibling; and My brother and I didn't really get along. And now I have no way to make that up.* The article closes with a few tips from youth who have had a sibling die on how adults around them can be helpful.

Grief and Love: Sibling Bereavement Program

14

Melanie Szigethy

This article describes elements of the Supportive Care Sibling Bereavement Program sponsored by the Children's Hospital in Pittsburgh. One important element is Camp Wakchazi, "an overnight away camp for bereaved siblings with a focus on healing, growth, and fun" designed for "Children struggling with the grief of losing a sibling [who] may not know other kids who have gone through something similar." The camp program is staffed by "Peer Counselors, a group of bereaved siblings, ages 18+, [who] are the role models of Camp Wakchazi. They offer support to the Counselors in Training (CIT)." Other elements described in this article include: "In 2020, due to Covid restrictions, the Sibling Bereavement Program pivoted and provided send home grief processing activities such as Camp in a Box for ages 7–18 and Camp Treasure Boxes sent to the 2–6-year-old siblings." Then, "In 2021 an opportunity to be together at the Dragon's Den ropes course was offered. The group was able to be masked indoors and remain socially distant." This was coupled with "a Bereaved Parent Virtual Support Group and a Fall Festival at Schenley Park with pumpkin painting for the kids." The Sibling Bereavement Program also includes a newly developed Teen Grief Group in the form of a 6-week structured program, a newsletter, and a planned weekend family camp.

A Window into Your World: Providing Virtual Grief Support for Siblings

16

Hania Thomas-Adams, MA, CCLS

This article describes the author's interactions with a six-year-old boy whose baby brother died shortly after birth. They talked about the boy touching the body of his deceased brother, whether or not he would want to go to the funeral a few days later, and the boy's animals and other toys. The author also discusses what she has learned about the needs of bereaved siblings and (for her) the unexpected value of virtual grief support. She offers these important observations: "Grief cannot be cured. It cannot be fixed, or denied, or distracted. Grief can, however, be heard. It can be held. It can be pounded in to clay and played out through stuffed animals and talked about intermittently while playing Zoom Charades. Every grieving sibling can benefit from a dedicated space to express that grief using the language of their heart. I have found that the virtual platform can be a way to create that space."

Considerations in Supporting Siblings of Medically-Complex Children

19

Jessica Sturgeon, MT-BC, HPMT

Using a case example of a 16-year-old brother of a child with medical complexities, this article describes four considerations to keep in mind when offering support to grieving siblings. These include the needs for: safety; self-expression; individualized care; and proper termination. The article concludes: "By allowing the space for the all of the aforementioned to occur..., there is an enhanced ability to support the family system as a whole and promote growth and healing moving forward."

Supporting the Family Including Siblings with a Brother or Sister in the NICU during the Pandemic

22

Denise Morrissey Chaveriat, BS, CCLS

This article describes how an NICU supportive care team made changes and adapted to the challenges of the COVID-19 pandemic on behalf of families and siblings. The author's conclusion as she looks back on all the adjustments and supportive efforts that were made is: "As I reflect on so many changes in the hospital, one thing remains the same: When you care for patients in the NICU, you realize the necessity of supporting the parents and siblings as well."

A Sibling Grief and Bereavement Toolkit**24***Allison Fuson, MS*

This article describes a capstone project undertaken by the author during the 2021-2022 academic year and inspired by her own experiences as a child encountering the death of her baby sister. The project was carried out in collaboration with the Pediatric Palliative Care Coalition (PPCC) of Pennsylvania, with the aim of providing a resource for the PPCC website that both families and medical professionals could access at any time. The specific form of the project involved developing a Sibling Grief and Bereavement Toolkit, an array of information and resources for anyone working with or supporting a bereaved school-aged child after the death of a sibling. The four main sections of the toolkit include information about: school-aged children's grief reactions related to death; emotional experiences related to death; therapeutic activities; and additional resources. A link to the toolkit on the PPCC website is provided.

Readers' Corner**28***Suzanne S. Toce, MD, FAAP*

In this latest iteration of her popular series of reviews designed to guide readers to new and important publications in the field of pediatric hospice/palliative care, Dr. Toce reviews a recent article in the journal, *Pediatrics*, entitled "Guidance for Pediatric End-of-Life Care." Dr. Toce summarizes the content of this article, explains who will benefit from this guidance, describes the issues the article addresses, shows where this guidance can be actualized, and points out when the process should be initiated.

Band Of Brothers Bound By Grief

Ann Fitzsimons, BS, MBA

Executive Director, here4U, Inc.

Farmington Hills, MI

ann@here4U.net

"Because brothers don't let each other wander in the dark alone." – Jolene Perry

Loss of a parent at any age, even as an adult, is hard, very hard. But when you're a child, and you've now lost the one person who has helped you navigate life since birth—your Mom—it's fraught with many deep-seated issues that often go undetected and untreated, and the consequences can last a lifetime. This is the story of three brothers whose mom died at an early age when they were only 11, 9, and 3 after having had a baby sister die at two weeks old about five years earlier. And while it's a story of sibling survival, it's not the happiest of endings that those who work in supporting bereaved children would hope for. Instead, it's a story of what happens when children, and maybe especially boys and their grief, aren't attended to when experiencing the loss of a loved one, especially when that person is their Mom.

In many families, Mom is the "glue" that holds everything, and everyone, together, and when that person dies, life changes dramatically. Old routines of doing homework, getting what you like to eat in your lunch (or even having a lunch made), having clean clothes to wear to school, etc., often fall by the wayside as the remaining family, Dad, and in this case, his three boys, have to learn how to do even the most basic of normal daily tasks alone. It is uncharted water, often fueled with chaos and turmoil, as Dad and the boys try to deal with all the physical, psychological, and mental challenges Mom's death has created for them. They are wounded and hurt and who is triaging all of their different needs? In this case—it was no one—and today, 16 years later, they are still paying the price of those early years of no processing of their grief and the pain that invited itself in to live in their very beings.

While there was a lot that was done well in preparing the boys for their Mom's passing (i.e., there was a social worker who came to the house to help them talk about Mom's illness and do memory-making activities), they were not told she was dying until a week before she passed away. And after being told, and having a social worker present to help them process what they'd just heard, it wasn't enough. They got to spend a weekend with their Mom at the home of a close relative where she had decided to receive her hospice care, complete with movies, popcorn, chats, games, etc., but then it was time to go home...to return to their "normal" lives at school and in sports. They did not return to see their Mom again before she died, which was four days later, because both Mom and Dad thought it was easier that way. For whom, I'm not sure. Their emotional and psychological trauma began here.

Their Mom had pre-planned her funeral and out of love and concern for them, did not have a role for them in the mass. She had felt it would be too difficult and she didn't know what kind of condition they would be in. Interestingly, a month later, at what the Irish call "The Month's Mind" mass, where you gather in prayer to remember the one who has died, they were very involved, at their request. They read the readings, assisted the priest during the offertory, and commented they'd wished they'd have gotten to do this during their Mom's regular funeral mass. When the priest commented how they must have been talking a lot about stories about their mom leading up to the Month's Mind mass, they replied that they hadn't and the priest looked visibly shocked. More signs of the trauma, and closed system at home, they were experiencing.

To provide context, in the days after the death, and through and after the funeral, as people reached out to offer help and support, their Dad's response was always he was "Fine" and that they were all "Fine," which of course, they clearly weren't. Because their Dad had chosen to shut down and move on as quickly as possible from her death, this is also the course he took for his boys---no grief or bereavement help, no support groups, no bereavement camps, no working with the pre-death Social Worker, nothing. They didn't talk about her, her clothes and personal effects were cleared from the house within a week after she died, and except for some pictures of her with the boys, it was almost as if it was easier to erase her memory, than for the Dad, or no less his boys, to actually have to sit in their grief and work through the immense pain they were all feeling silently in their own hearts and minds collectively as brothers, and individually as young boys.

There were walls put up from those trying to help as the boys were continually kept away from family members who could have helped--who had offered to take them to memorial services, grief camps, counselors, and the like. The answer was always the same, "No." As the years went on, it became evident what toll this was taking on each of the boys. The oldest, who is the most sensitive, shut down and turned inward, drawing ghoulish dark figures with no faces as a way to express his fascination with death and all things dark. The middle brother was maybe faring a little better as his ADDHD diagnosis required him to see a counselor to get his prescription refilled, so at least he had access to someone he could talk to IF he wanted to, or would. And the youngest simply didn't know any different. At such a young age, he didn't have many, if any, memories of his Mom, so life with his Dad and adult babysitter from next door (who became a surrogate Mom to him, to all of them, really) was all he really knew. And they all got lost in the blood, guts, and violence of the Call of Duty video game--clearly a form of escapism from the realities of their real, everyday life of pain and loss.

Fast forward to today. They are now young men aged 27, 25, and 19, trying to make their way, or not, in this very tumultuous world. While at many times in their lives, they've had only each other to lean on to get themselves through life, it clearly wasn't enough, and the cracks in their lives are all too evident.

The oldest brother graduated college with a degree in graphic arts, but has never worked in his field. He has quit his last warehouse job, is severely depressed and withdrawn from society, and has no self-esteem. He is angry at how he is now and how he got here, and blames family members for not being there when he needed them to make sure he (and his brothers) all turned out OK. He has insisted for years he can "work through this himself" and each day, spirals further and further down. After hitting what may have been rock bottom for him, he has finally started to see a therapist and the hope is that he stays the course as there is much for him to unpack, process, and integrate from all this in a way that improves his physical and mental health.

The middle brother is in college working towards a degree in History. He has no idea what he'll do after he graduates with that degree. He had some trouble with the law in high school which will likely follow him for a long time, and in the end, all he wants to do is become a Comedian, to put on another persona to hide all that is really going on inside him. He works part-time at a fast serve restaurant, goes to school, and plays Call of Duty (or whatever the latest blood & guts video game is). His life is very small.

The "baby" brother is now 19 and in college working towards a nursing degree. He has no known memories of his own of his Mom, and for that, he is really starting to grieve, as he begins to recognize he has lost both his past and his future without her. He has had probably a better life than his two brothers as his Dad remarried when he was still fairly young, so he had a female presence in his life to help care for him and because he didn't remember his Mom, he didn't feel like he was betraying her like his brothers did, by letting her be a presence in his life.

While these boys have faced the loss of their Mom (and baby sister), and all it brought to their lives, often alone, there have been many moments, when they have leaned on and into each other. One such moment recently is when these boys attended a male cousin's wedding—a peer with whom they were close—and while it was a happy family affair, it was also marred with sadness as each was poignantly reminded of all they'd lost when their cousin took to the dance floor to have that memorable Mom/Son dance. They commiserated and shared with each other how they'll never have that, or never have their Mom see any children they have be born and grow up, or just get to be that family they all so desperately seem to be seeking to be a part of to make them feel whole again.

The intent of this piece was not to share any evidence-based practices or pearls of wisdom of how to support siblings in their loss of an important loved one like a parent, but instead, to shine a light on what happens when siblings in a family aren't cared for, attended to, supported in the processing of their grief and bereavement during difficult healthcare journeys with family members, whether another sibling or a parent. While their Dad would have made it difficult, I can't help but wonder if a lifeline had been thrown by a professional while their Mom was in the hospital with her terminal diagnosis, whether it have made a difference. A supportive Aunt did request social work help when they were being told their Mom had cancer, as that's what their baby sister had died of and there was concern their Mom's diagnosis would be a trigger for them and one that potentially would need to be de-escalated by a professional, not a Mom heartbroken she was going to be leaving her three young boys, or a Dad unable to accept this diagnosis himself.

My wish in sharing this story is that adults, whether professionals or family/friends, can find any way possible to support siblings during these difficult journeys in their families because oftentimes, families will be more open to listening to guidance from professionals on the outside, than from family members on the inside. Any interaction, however small, could be that crack that starts to let the light shine on supporting these siblings, in this case, brothers, as they try to not let each other wander in the dark alone.

Mourning The Sister I Never Knew

Donna Lynne Schuurman, Ed.D., FT

Lynne's sister

Sr. Director of Advocacy & Training

Executive Director emeritus

Dougy Center: The National Grief Center for Children & Families

Portland, Oregon

donna@dougy.org

My father's only sibling died from Scarlet Fever when she was 15. He was a Merchant Marine, on a ship off the Horn of Africa at the time, 19 years old, and hauled home to Philadelphia for her funeral. Doris got a sore throat on a Friday night and was dead on Monday. My mother, who was 16 at the time, and dating my father, stayed with her Friday night instead of going to the school football game they'd both planned to attend, not knowing the severity of Doris' illness, but not wanting her to be alone.

A couple of years later my parents, now married, had their first child, a girl, whose name was Lynne. Lynne died on June 20, five days after her birth, from Ectopia cordis, a condition in which babies are born with their heart partially or fully outside their bodies. Ectopia is from Greek, meaning "in the wrong place/out of place" and *Cordis* from Latin, "of the heart." The chances are eight in one million for such a birth; and the odds of living are low, 10%.

My mother was 19, bereft. Her Irish Catholic father told her it was her fault because she married a German Methodist, but I didn't learn that until the year Lynne would have been 60, when with great trepidation I called my mother to ask if she'd tell me the story of Lynne. It took that long for someone to ask.

A year after Lynne died, my parents had a boy, Stephen. Three years later another boy, Bradley, and then two after that, me, the baby of the family, and the only surviving girl. I like to think they kept trying until they got the best, but the truth is they kept trying because my mother still wanted a girl.

Growing up my mother started to get moody, withdraw, and spend time in her room as June rolled around. My father would say "it's about the baby," and that she'd be fine and back to herself by the 4th of July. We didn't question him, or it, or ask about "the baby" or even think to. There was an unspoken covenant that it was not to be discussed. All I knew was the baby was a girl, and that she died shortly after birth.

I'm a little embarrassed to admit that I was 17 years into my role as the Executive Director of Dougy Center: *The National Grief Center for Children and Families* before it even remotely occurred to me to ask about the baby's death and my mother's experience. My father took his experience to the grave, and I regret never having asked him. The unspoken agreement to stay silent, like steel, runs hard and strong. Somehow, for reasons I no longer remember, I realized my sister would have been 60 years old that year, and I got to thinking about how things might have been different had she lived. I would have had an older sister! Someone to look up to, who would have taken me under her wing (against my brothers' not always nice behaviors). I decided to call my mother, 3,000 miles away, which felt like a safe distance as I anticipated her continuing the steely silence, sloughing it off as "a long time ago" or worse, just hanging up on me. Raised in a staunch and unforgiving home, my mother was not prone to vulnerability.

I called. She answered. I didn't waste time; afraid I'd chicken out. "Mom, I was just thinking that Lynne would have turned 60 this year, and I wondered if you would be willing to tell me the story of her life, of what happened, of how her death affected you..."

Three and a half hours later, I hung up the phone.

No one had ever asked.

At 79, she'd carried this burden of guilt and pain for 60 years. The story is a long one, as all good stories are, for another time, but I'll share a few of the memorable aspects. She was able to hold the baby after her birth, for a brief time, but then they took her away. While still in the hospital, unsure what was happening, with no one providing answers, her father eventually came in her room to tell her the baby had died, and that "everything was taken care of." What that meant was that the baby's body was disposed of, and all signs that a baby was coming back to my parent's apartment were removed. That's when he also decided to tell her it was her fault. And that they didn't want to waste the name, Lynne, so he put my mother's name on the death certificate, Clare.

No funeral, no friends. At that time, it was shaming to be young and pregnant and then lose your baby, and the heaping of religious guilt didn't help. She and my father never spoke of it again. She was terrified when she became pregnant again, terrified the baby would be deformed, and relieved when he wasn't. Another baby boy and then me, a girl. She said she tried to assuage her pain and guilt over Lynne's death by convincing herself she wouldn't have had me had Lynne lived.

I recognized how my parent's unaddressed grief cast a shadow over all of our lives, with my mother's in-and-out depression, my father's denial, and our shared pact for the topic Not To Be Discussed. How different it could have been had they been able to mourn their baby in the supportive arms of family and friends.

I got off the phone both emotionally exhausted and emotionally charged, grateful for my mother's trust in me, and activated by an understanding of her, her parenting, our family issues, my own troubled journey. And I wrote a poem, for Clare Lynne, the name my mother called her dead baby. Here's a portion of it:

*My sister,
How strange the sound of a word
I never got to say.
My heart wasn't in the right place either
And yet I got to stay.
In some strange way your spirit
Reaches out to me
Across these years
And urges me to live
To give your voiceless life a name.
The name I claim.
Oh Lynne, you poor misshapen child.
I got my life
Because you died.*

My parent's divorce papers were finalized on their 40th wedding anniversary. I asked my mother when, in her mind, the marriage was over. "Do you really want to know?" she asked. "Of course," I replied. Here's what she said: "I knew our marriage was over when I came home from the hospital without the baby, and we could never talk about it."

Unaddressed grief.

Steely silence.

Secrets and shame.

Unique Attributes Of Sibling Grief: “People Look At Me With A Dead Brother Face”

Amy Benner LaBelle, MSW

Philanthropy Director

Annie's Hope – The Center for Grieving Kids

St. Louis, MO

amyl@annieshope.org

Sisters Frannie and Dell were in junior high when Cindy, their beloved 18-year-old sister, succumbed to Sickle Cell Anemia.

At the age of 14, Kay's brother became a gun violence statistic. A TV news camera recorded Kay explaining that Vinnie was her “only brother.”

When 7-year-old Andre's infant brother died from Shaken Baby Syndrome, his family told Andre the baby died due to illness. They did not know how to explain why a person would intentionally harm a 2-month-old.

Ike and Noah survived the auto accident that killed their brother, Jason. When she lost control of the car, their mom's blood-alcohol level was three times the legal limit.

Ben was 10 when he arrived home from school and discovered his older sister's body. After years of unsuccessful interventions, she took her own life.

Jack, age 12, and Ellie, age 14, were home when their infant brother suffocated in an adult's bed. Ellie's attempts at CPR failed to revive her baby brother.

The kids and situations represent thousands of grief stories shared every year with Annie's Hope. After eleven years at Annie's Hope, I still find inspiration in the courage of grieving kids. Despite indescribable heartbreak, their kindness and generosity toward peers are unwavering. More than 3,600 kids and adults participate annually in the grief support programs of Annie's Hope, The Center for Grieving Kids. Founded in 1998 by a pediatric oncology nurse, our mission evolved from the community's desperate need for child-focused support to help siblings, friends, and other relatives navigating grief.

I was a young adult when the closest of my three brothers died unexpectedly. One minute he was standing next to me at our office, and a few hours later, my life's trajectory was forever altered. Twenty years later, I remain on a grief journey that is never ending and unpredictable. My heart still aches for all of us missing Johnny, but I'm grateful that I can remember. In times of sadness, I think of the kinship I share with grieving siblings of Annie's Hope. It is a gift I cherish, but also one I never wanted.

Each year in the St. Louis region, 3,874 kids (Annie E. Casey Foundation, 2021) are newly bereaved, and 1,860 of them grieve the deaths of siblings. Brothers and sisters face challenges that are unique to the experience of sibling grief. A child's perception of the world as safe can shatter with sibling loss. The relationships formed with siblings, whether positive or negative, define an individual's concept of family. Siblings are the longest-lasting and most profound connections to our past (Carroll, 2017). Their loss creates an unfillable void that disrupts the family space and requires renegotiation of roles. Establishing new hierarchies may prove especially challenging in families where sibling relationships are extremely close or adversarial. Consequently, grieving siblings struggle with guilt, regret, anger, and anxiety.

Because the death of a child is perceived as an outlier in the natural order of human life, family and friends often prioritize care for parents and leave the youngest family members navigating grief in solitude. The grief of siblings is compounded when they are disenfranchised. Bereavement's effects are further exacerbated if the parents' grief hinders their ability to care for and comfort siblings. The absence of reassurance and attention is experienced by so many surviving siblings that mental health professionals frequently refer to brothers and sisters as "forgotten mourners" (Bowen, 2019).

Unsupported grief during critical phases of child development creates vulnerability to long-term challenges. Grieving kids exhibit intense anger, difficulty sleeping, somatic complaints, anxiety, fear, and inability to focus. Older siblings may engage in risky behaviors, withdraw socially, or become argumentative when lacking support for their grief. For 7%, grief becomes complicated. Features include obsession with death, constant thoughts about the deceased, inability to function daily, and incessant worry (Shear, 2012).

At 15, Cara was a typical teen expressive, honest, and friendly. When her younger brother's cancer advanced, she withdrew from social events and activities. It was clear to Cara that her teachers and friends did not know what to say, and sometimes their discomfort caused them to avoid her. Feeling alone, Cara watched her parents devote every bit of their energy to Michael's limited time. She was grieving, too, but in her mind, Cara was an obstacle in her mom and dad's efforts to focus on Michael's comfort. They spent every moment at her brother's bedside until he died. Cara was quiet, angry, and guarded when she arrived at Annie's Hope for a week-long grief support camp with other teens. In a moment of brutal honesty, Cara admitted to cabinmates that she was "Sick and tired of people looking at me with a 'Dead Brother Face.'" As new friends nodded in agreement, it occurred to Cara that she was not the only one who encountered friends and neighbors who looked upon her with pity, not knowing what to say.

Damon was 9 years old when his beloved older sister unintentionally overdosed. For Damon's mom, a single parent, the loss was overwhelming. Distracted by constant emotional turmoil, she could not offer Damon the information, comfort, and attention he needed. Damon ran from home three times before an aunt noticed his distress and intervened. The aunt offered temporary housing and ensured that Damon attended support groups while his mom sought help. Grieving peers helped Damon express his fear and anger through supervised activities. Breaking plates, punching a pillow, and tearing paper allowed the second grader to release emotion. When Damon heard friends in group ask questions about the loved one's deaths, he knew he was not alone in his grief.

Sibling deaths may increase the risks for future health problems and negatively impact adulthood. Threats to emotional and behavioral stability brought about by sibling deaths may even outweigh the impact of parental death (Miller, 2020). To ensure grief remains on a healing trajectory, Annie's Hope offers facilitated peer support tailored to developmental levels. Structured activities allow grieving siblings to connect with other children who understand the bereavement experience. In small groups, kids share stories and learn from peers they trust. Acceptance and support generate opportunities for siblings to rediscover confidence, establish new relationships, and develop healthy coping mechanisms.

Kids learn to identify and express feelings through support group activities. 'Words that Hurt – Words that Help' is an exercise for school-age and teen participants. Group members share the sentiments, actions, and words that cause pain. Like Cara's reference to a 'Dead Brother Face,' siblings are free to add anything in the hurtful category with no judgment from peers. Statements and actions that validate a griever's experience go on a page titled 'Words that Help.' Themes are common regardless of age.

Kids find it hurtful when peers nullify their feelings, imply that showing emotion is inappropriate, or make disingenuous claims. Past group members cited as examples: "Stop crying. You'll be okay." "It's time to get over it," and "Stay positive, and don't be sad." Further, grieving siblings were honest about the upsetting nature of apologies and platitudes. They prefer people avoid "I'm sorry," because it implies responsibility or regret at bearing witness to grief. "Your loved one is in a better place." "Things will get better." and "I understand how you feel" also made the hurtful list. However, kids admitted that it was equally frustrating when people altogether avoided conversations about grief and the deceased person.

Helpful words and actions frequently cited by group members include sharing a memory of the deceased person, looking at photos or videos with the bereaved, expressing genuine interest in the welfare of a mourner, listening without commentary, and simply being present. Other actions endorsed by grieving siblings and kids missing significant relationships include asking what the griever needs, offering space for kids to accept or decline companionship without judgment, and initiating one-on-one conversations in private settings. Often the only way to companion a grieving child is simply to be present and attentive.

The number of bereaved youth calculated as 17% of the population under age 18 averaged across 18 years of childhood. The occurrence of sibling death is calculated as 8% of the total child population. Given the prevalence of these deaths and bereavements, attention to support of surviving siblings is crucial.

References

American Academy of Child & Adolescent Psychiatry. (2018, June). Facts For Families: Grief and Children. Retrieved June 21, 2022, from https://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/FFF-Guide/Children-And-Grief-008.aspx

Annie E. Casey Foundation. (2021, June 21). KIDS COUNT Data Center: A project of the Annie E. Casey Foundation. Retrieved June 20, 2022, from <https://datacenter.kidscount.org/>

Bowen, E. "Sibling Loss: Experiencing Grief through a Child's Eyes." AAP.org, *American Academy of Pediatrics*, 26 Feb. 2019. Retrieved June 16, 2022, from <https://www.aap.org/en/news-room/aap-voices/sibling-loss/>.

Carroll, E. "When Children Lose Siblings, They Face an Increased Risk of Death." *The New York Times*. (2017, July 31). <https://www.nytimes.com/2017/07/31/upshot/when-children-lose-siblings-they-face-an-increased-risk-of-death.html>

Miller, J. (2020, October 14). One-third of young people in low- and middle-income countries have lost a sibling. *USC News*. Retrieved June 18, 2022, from <https://news.usc.edu/177433/sibling-death-young-people-low-middle-income-countries-usc-research/>

Shear M. K. (2012). Grief and mourning gone awry: Pathway and course of complicated grief. *Dialogues in clinical neuroscience*, 14(2), 119–128. <https://doi.org/10.31887/DCNS.2012.14.2/mshear>

Yu Y, Liew Z, Cnattingius S, et al. "Association of Mortality with the Death of a Sibling in Childhood." *JAMA Pediatrics*. (1 June 2017;171(6):538–545.) doi:10.1001/jamapediatrics.2017.0197

Don't Forget Us! Voices Of Youth After The Death Of A Sibling

Donna L. Schuurman, Ed.D., FT

Sr. Director of Advocacy & Training

donna@dougy.org

Monique B. Mitchell, Ph.D., FT

Director of Training & Translational Research

monique@dougy.org

Alysha Lacey, M.A., FT

Director of Program Services

alysha@dougy.org

DOUGY CENTER: THE NATIONAL GRIEF CENTER FOR CHILDREN AND FAMILIES Portland, OR

Since our founding in 1982, Dougy Center: *The National Grief Center for Children and Families* has provided grief support in a safe place where children, teens, young adults, and their families can share their experiences before and after a death. We've provided training and community responses locally, nationally, and internationally, based on what we've learned from over 55,000 participants in our grief support groups over these past decades. At the height of our local services, more than 550 children, teens, and young adults as well as 450 of their parents or adult caregivers participated in 70 ongoing groups each month based on the person who died (parent, sibling), the age of the youth (groups for children 3-5, 4-8, 6-12, teens 10-14, 13-17, and young adults 18-25, 25 and up), as well as some specialized groups for those whose person died of suicide or homicide. Pivoting to virtual groups during the years of the COVID-19 pandemic restrictions reduced the number of participants who chose or were able to attend virtually, though the backlog of families grieving a death during that time quickly filled our groups when we resumed them in-person.

Over the years after we first started our bereavement groups, we often heard many stories of regret from family members who had someone die after an extended illness or disease. They commented on the things they wished they'd asked doctors and medical personnel when their person was alive, ways to better cope as a family with the impact of the person's illness on their children, and how to keep memories alive even as their loved one's life was fading. In response to their experiences, we surveyed families to see if they would have attended a group prior to their person's death. The overwhelming response was, "Yes!" With their recommendations, we piloted groups for families who had a member with an advanced serious illness like advanced stage cancer, ALS, and other diseases. As the groups progressed, families urged us to continue offering this service and our "Pathways Program" was born. Pathways provides peer grief support groups for children ages 3 and up, as well as a caregiver group, and a group for the persons with the illness, if they are able to attend.

Dougy Turno, the boy for whom Dougy Center is named, would have been proud. His desire to help other kids even while he was dying inspired our Founder, Beverly Chappell, to start a place where kids could be with other kids and share their experiences. Although his life ended after 13 years, his legacy continues to reverberate in the hundreds of programs Dougy Center has trained worldwide.

Dougy was diagnosed with a brain tumor at the age of 9, and the lives of his parents and siblings were forever changed in the years of his illness and after his death. The impact of losing a sibling has received less attention from researchers than that of losing a child. However, there is increasing recognition that the death of a sibling can have profound implications for surviving brothers or sisters. Researchers have stated that many people are not aware of the devastating impact of sibling loss. Consequently, siblings may receive little support or understanding from those in their social environment. This may contribute to a sense of isolation and alienation from others feelings known to be prevalent among surviving siblings (Funk et al., 2018). Studies have demonstrated that sibling loss is linked to serious physical and mental health problems (Funk et al., 2018). For example, young adults who lose a sibling are significantly more likely to report higher levels of somatic symptoms, depression, and painful feelings of grief than those who lose a close friend (Herberman Mash, Fullerton, & Ursano, 2013). It has also been shown that the loss of a sibling is associated with an elevated mortality risk (Rostila, Saarela, & Kawachi, 2012).

The research is compelling, ongoing, and helps inform our program and services, and for that we are grateful. Research-based evidence is important, and so is practice-based evidence, with the voices of youth with lived experience helping us understand their needs and better serve them. We'd like to share some themes that have emerged from our sibling grief support groups over the years, along with a few of their stories. This is not a comprehensive list, but it does highlight some of the most common concerns youth have shared.

Themes Youth have Shared after the Death of a Sibling

I feel like I lost my parent or parents when my sibling died.

The death of a child is a devastating loss for any parent, and how parents cope is a powerful influence on shaping their surviving children's responses. Of course, children will respond in different ways depending on their chronological and developmental age, their personality, the circumstances of the death, the relationship they had with their sibling, their social support, cultural traditions, and other factors. But it is not unusual for youth to share that when their sibling died, their parent, parents, or adult caregivers changed dramatically, were "lost in their grief," and the entire family dynamics shifted. As flight attendants instruct passengers, it is important to "put your own oxygen mask on first" before helping others. We encourage parents who are grieving to do their best to attend to their own needs as it better equips them to be there for their children.

Now I have to be the 'perfect' kid.

One of the changes some of our adolescents and young adult participants have shared is feeling pressure to be "perfect" to "make up for" the pain the family has experienced because of the death of their sibling. That pressure may be self-imposed, as 14-year-old Shar'ee explained: "My mom and dad just suffered so much when my brother Kamil died. I just can't add any more pain or problems to what they already have, so I have to get good grades, stay out of trouble, and make them proud." Sometimes the pressure is externally-imposed, illustrated through Bradley's experience: "When my older brother Sam died, a lot of people told me since I was now the 'big brother' to my two sisters, I had to be strong and take care of them. I mean, I was only 10 years old, and I felt like people were expecting me to be an adult."

My parent/parents are now super over-protective of me.

A natural consequence of the death of a child is for a parent to feel anxious and concerned about the safety of their other children. Sometimes this results in frustration for their children, especially teens, who sometimes express that the shift in over-protectiveness "messes with my life" as 16-year-old Sharynne shared in her sibling loss support group. "I can't leave the house without my mom worrying and constantly calling me to see where I am, what I'm doing, and when I'm coming home. I mean, I want to hang out with my friends without her calling me all the time!"

I have had to grow up faster than my friends and I feel like I lost part of my childhood.

At the other end of the spectrum, a lot of kids talk about feeling like they lost out on being a kid. Drey, 16, shared that "my sister died right after I got my driver's license, and I suddenly became 'the man' who had to drive my younger siblings everywhere. I had to take them to games and pick them up after school, and I couldn't hang out with my friends as much like before. I mean, I went from child to 'man' in a matter of months, and completely skipped the fun part, the part of being a teenager! It's been really hard, and I feel different from my friends, and a lot of them I just don't see any more."

Identity issues: My only sibling died...am I still a _____?

For kids whose only sibling died, the ambiguity of their "role" can present turmoil. Role ambiguity, experiencing ambiguity about one's role within a family after dynamics or situations change, is a common experience for children who experience the loss of a sibling (Mitchell, 2016). When a parent's only child dies, the parent may wonder "Am I still a parent?" Similarly, when an only sibling dies, the surviving sibling is left with a difficult dilemma: "Am I still a brother?" "Am I still a sister?" With respect to youth who identify as "non-binary," "Am I still a sibling?" Some youth have expressed their sadness and disappointment at not having the chance to be a brother, sister, or sibling, and how that hole in their lives can never be filled. As Packman, Horsley, Davies, and Kramer (2006) have stated, "Losing a sibling means the loss of a companion, confidante, role model, and friend. Siblings' identities are intricately connected because they share similar histories so that when one of them dies, the survivors essentially lose part of themselves" (p. 820).

I'm afraid everyone around me will die. Including myself.

While it's normal and natural to have increased anxiety after a sibling dies, it can also be problematic. Fifteen-year-old Savon's younger sister died two years after being diagnosed with leukemia, following multiple treatments. "She didn't do anything to deserve that. It's like one minute you're just living your life, and the next you have this fatal illness. It could happen to me too, or to anyone, and I have nightmares about it all the time."

I wonder if they ever wish it were me who died instead of my sibling.

It is not unusual for a child to wonder if their parent(s) ever wish they had died instead of their sibling. This could be a heightened concern for any child or teen who feels like (or has been labeled as) "the problem child." Abon, 14, whose 16-year-old sister Sabria died from a lung disease, illustrates this issue: "Sabria was, like, the perfect person. Her grades were all As, she was in the Honor Society, and everyone loved her. I'm kind of like the reverse of her, I mean, I'm a nice enough person, but I get average grades, and I don't really have a lot of things I'm good at. So, it's like, I wonder, I just wonder, if my parents ever wish I had died instead of her. It definitely crosses my mind."

My brother and I didn't really get along. And now I have no way to make that up.

Not all sibling relationships are amicable, and some children and teens carry unaddressed guilt, regret, or self-blame when a sibling dies. Roberto, 11, shared that he used to tease his younger brother and sometimes make him cry. "I wish I could tell him I'm sorry. I wish I was nicer to him." Some youth go as far as blaming themselves for their sibling's death, by something they did or failed to do, even if it is objectively irrational. They don't always share these concerns with the adults around them, and sometimes weren't aware they had carried them until others in the group share. We try in our groups not to refer to every person who has died as a "loved one" as it does not create a safe space for those to share when persons may have had a tumultuous relationship, or don't define their relationship as one of "love."

These are a few of the topics youth have shared in our groups for those who have had a sibling die. Here are a few tips on how adults around them can be helpful:

- Try to listen without interrupting — just listen!
- Avoid responding with judgement ("You shouldn't feel that way.") or advice giving ("What you need to do is...")
- Find ways the child or teen can engage and express themselves that aren't only sitting and talking through art, movement, music, etc.
- Many kids will open up while they're in a vehicle, playing a game, over an ice cream, or on a walk.
- Bring up the name of the sibling who died and share memories.
- Find ways to remember the sibling who died.
- Ask them if they've ever felt any of the concerns shared here.

Shifting and adapting to the changes the entire family experiences when a child/sibling dies can be a challenging time, with no clear "directions to follow" that apply in every situation. Finding outlets and creating open communication for siblings, the often "forgotten grievers," is an important consideration as the family navigates their "new normal."

For more information including Tip Sheets, resources for school personnel, medical staff, and others, please visit us at our website, www.dougy.org.

References

Funk, A. M., Jenkins, S., Astroth, K. S., Braswell, G., & Kerber, C. (2018). A narrative analysis of sibling grief. *Journal of Loss and Trauma*, 23(1), 1-14. <https://doi.org/10.1080/15325024.2017.1396281>

Herberman Mash, H. B., Fullerton, C. S., & Ursano, R. J. (2013). Complicated grief and bereavement in young adults following close friend and sibling loss. *Depression and Anxiety*, 30(12), 1202-1210. <https://doi.org/10.1002/da.22068>

Mitchell, M. B. (2016). The family dance: Ambiguous loss, meaning-making, and the psychological family in foster care. *Journal of Family Theory and Review*, 8, 360-372. doi: 10.1111/jftr.12151

Packman, W., Horsley, H., Davies, B., Kramer, R. (2006). Sibling bereavement and continuing bonds. *Death Studies*, 30(9), 817-841. <https://doi.org/10.1080/07481180600886603>

Rostila, M., Saarela, J., & Kawachi, I. (2012). The forgotten griever: A nationwide follow-up study of mortality subsequent to the death of a sibling. *American Journal of Epidemiology*, 176, (4), 338-346. <https://doi.org/10.1093/aje/kws163>

Grief And Love: Sibling Bereavement Program

Melanie Szigethy

Coordinator, Sibling Bereavement Camp
Supportive Care Program
UPMC Children's Hospital of Pittsburgh
Pittsburgh, PA
melanie.szigethy@upmc.edu

"We now know grief and love are always together," stated a teen participant in the Sibling Bereavement Program of UPMC Children's Hospital of Pittsburgh. This statement helps guide the programming that provides activities that offer respite from feelings of grief. The program started in 2018 and offers many modes of outreach to bereaved families such as Camp Wakchazi, whole family gatherings, Teen Grief Group, and a quarterly newsletter. The goal is to provide a variety of activities either in a group format or those that can be completed at home as a family or individually. Offering coping skills and a means to process and honor the death of child is an important component of the Supportive Care Sibling Bereavement Program.

Camp Wakchazi is an overnight away camp for bereaved siblings with a focus on healing, growth, and fun. Children struggling with the grief of losing a sibling may not know other kids who have gone through something similar. Peer Counselors, a group of bereaved siblings, ages 18+, are the role models of Camp Wakchazi. They offer support to the Counselors in Training (CIT) and lead the younger campers in grief group discussions about what it means to be a bereaved sibling, how to cope on the hard days, and how to be the best version of themselves. The CIT program evolved for campers ages 15-17 to learn leadership and group management skills. They meet once a day to have small group discussions on problem solving, peer relationships, and coping skills. Camp Wakchazi is in an outdoor setting to connect with nature, pursue high rope challenges, and participate in water sports. Woodworking projects, painting, and music are also offered to enhance the camp experience. A Peer Counselor stated, "Camp Wakchazi gives me the opportunity to be the best version of myself while providing the space to heal as well. I have been with the camp since I was sixteen as a camper and then Peer Counselor and it is always a bright spot on my calendar. Healing, encouragement, and growth all come from Camp Wakchazi and the people who make it happen." Volunteer Staff are a wonderful and familiar support to the campers especially if they met while the sibling was an inpatient.

In 2020, due to Covid restrictions, the Sibling Bereavement Program pivoted and provided send home grief processing activities such as Camp in a Box for ages 7-18 and Camp Treasure Boxes sent to the 2-6-year-old siblings. A mother of a 3-year-old sibling stated, "These activities help to keep the memories alive so that our daughter will know her sister." The boxes contained arts and craft supplies to help the members explore their feelings associated with the death of their sibling and create a memorial to honor them. Gross motor yoga exercises, a High Intensity Training workout, and mindfulness instructions were included as coping activities. Some of the activities were to be completed independently and others were to be completed with a family member or friend. One of the teen members stated, "It would have helped to process my feelings if I had something else to focus on like school and sports, but Covid stopped all those things." Providing at-home support to those grieving is vital.

In 2021 an opportunity to be together at the Dragon's Den ropes course was offered. The group was able to be masked indoors and remain socially distant. The participants challenged themselves on the high ropes course, zip line, and then outdoors with team building games on the lawn. The parents observing the kids suggested more outdoor gatherings so that they, the parents, could have time to talk amongst themselves. This was achieved through two options: a Bereaved Parent Virtual Support Group and a Fall Festival at Schenley Park with pumpkin painting for the kids. Both options provide time for the parents to talk and support one another. The online virtual group utilizes Microsoft Teams app to meet once a month. The parents discuss the child that died, finding meaning, re-discovering who they are, and sharing current events that impact their grief journey. Most notable is how the participants have bonded and look forward to the group events to be together. A parent commented, "This program not only helps my son but is like my lifeline to my healing. We don't have much family support, so I am truly grateful." The Virtual Support Group is co-hosted by a bereaved parent volunteer that can offer advice and support based on her experience. This volunteer also does follow up phone calls as needed to participants of the group.

Another element of the Sibling Bereavement Program is a newly developed Teen Grief Group that also utilizes Microsoft Teams app. This is a 6-week structured program that was developed with Child Life Specialists to cover: self-reflection, grief, coping skills, peer relationships, family dynamics, and more. Guest speakers, who are now young adult bereaved siblings, shared their grief journey experience at the beginning of the meeting followed by questions and discussions. One guest speaker noted, "Every year I think about it differently. You are hit with the death all at once and then as you age you sort it out piece by piece." The Child Life Specialist led an activity each week and provided an outlet for conversations amongst the teen participants. Send home activities included a process journal, grief worksheets, air dry clay, and snacks.

The quarterly newsletter was created to keep families informed of resources for bereavement and provides an outlet for those that are not able to be together due to location. The newsletter is delivered to families in 28 states. Some families do not use the internet; therefore the newsletter is provided on paper and sent through the postal service. A mom said, "I love the newsletter; knowing that there are other families that feel the same way I do. So sad for our loss but comforted in knowing we think of each other." The newsletter highlights new staff members, upcoming local and national events, and current resources for grief support. Included are articles about journaling exercises and mindfulness activities, as well as articles written by staff or submitted by families that are willing to share the circumstances about their child's death and how they are coping.

The Sibling Bereavement Program continues to expand by taking into consideration the needs of the bereaved siblings and their families. New for 2022 is Family Camp, a weekend at Camp Soles, Somerset County, for the whole family. This program will offer activities in nature that will allow the families time to be together away from their regular schedule, be able to connect with other families, and participate in a memorial activity. Hiking, waterfront activities, rope challenge course, relay games, and family style dinners and s'mores will round out the weekend of growth.

Providing activities that enhance peer relationships with others that "know" what sibling loss is about is a major component of the Sibling Bereavement Program. By offering family-friendly activities for parents to be in a group that understands loss and suggesting a variety of coping skills and taking time for self-reflection will allow growth and development. Connecting children with one another and equipping them with healthy coping strategies can impact the course of their lives. Providing families an outlet to gather, reminisce about their child that died, and grow in new relationships may have a positive outcome to a negative circumstance. Currently the program is free of charge to families who participate thanks to generous donors to the Sibling Bereavement Program at UPMC Children's Hospital's Supportive Care Program.

A Window Into Your World: Providing Virtual Grief Support For Siblings

Hania Thomas-Adams, MA, CCLS

Child Life Specialist II, PACT Team
UCSF Benioff Children's Hospital
Oakland, CA
Hania.Thomas-Adams@ucsf.edu

At first, all I can see on the screen is a ceiling fan rotating slowly. It slows and stops, indicating that someone just out of the screen has turned it off.

"Hello?"

A little hand appears. My view changes as whomever is on the other side picks up the device. Suddenly I am looking at the face of a boy sitting on a bed. He is about 6 years old, wearing pajamas, and surrounded by stuffed animals. He says hello back. I tell him my name and he tells me his. I am introduced to each stuffed animal individually. Everyone is assembled.

"I'm someone who talks to brothers and sisters when they have something sad happen in their family," I say. These were words I had previously discussed with the boy's mother and which mirrored the language being used in their home.

The little boy nods vigorously and leans closer. "I had something sad happen in my family. It happened to my baby brother. My brother died."

I ask him if there is anything he would like to tell me about his brother. He tells me that his brother was only three days old. He tells me that something happened to his brother when he was born and he didn't get enough air, so he died. He tells me that he got to see his brother's body and that he touched his feet and his hair.

"You saw his body after he had died," I reflected.

The boy paused, remembering. "He was little."

Over the course of a half-hour, I was further introduced to about 20 more stuffed animals in various rooms of the house as well as two actual cats. The little boy's mother joined the call and together we talked about what was going to happen at the baby's funeral, which was scheduled for later in the week. The boy said that he wasn't sure if he wanted to go, and we said that was OK and that he didn't have to decide right now. In true kid fashion, he stepped in and out of his grief, moving from the topic of funerals to the topic of race cars and back again. I moved with him. We wondered if his purple car was faster than his blue car and which was more aerodynamic (his word, not mine). The blue car won. We wondered what his brother's favorite color would have been. He guessed "Blue, like me." When I asked if there was anything he was still wondering about or feeling confused about, he asked what color his brother's ashes would be. At the end of the call, I told him that we could talk again if he ever wanted to.

Later that week, his mother emailed me and told me that the boy had decided to go to the funeral, had chosen something meaningful to bury with his brother's ashes, and had asked to help with many aspects of the ceremony. I have not spoken with either of them since, but I think of them often.

As a Palliative Care Child Life Specialist (CLS) in this post-2020 world, I have incorporated virtual sibling support into my work to a far greater capacity than I would have anticipated when first starting my career. The unique needs and perspectives of siblings have always been a central focus of mine, and the concept of meeting siblings where they are has taken on a deeper meaning as I have been able to literally "meet" them in their homes, albeit through a Zoom screen.

When a child loses a sibling, every aspect of their world is irrevocably changed. In losing a sibling, they often also lose a friend, an ally, a playmate, and a witness to their experience of family life. Their identity and role within the family may change as they suddenly become the youngest, or the oldest, or an only child. Their parents may also change significantly as they experience their own grief, adding loss upon loss. A child is left mourning not only their brother or sister, but their family structure, normal routines, and their parents as they know them to be. Siblings may be left out of family grief rituals and conversations in an effort to protect them, which can leave them feeling confused and alone with their grief. They may experience guilt from remembering every negative thing they ever thought about their sibling, from feelings they may have after the death, or because they are misguidedly blaming themselves for their sibling's death. Grieving siblings often experience the biggest, most intense emotions they have ever felt.

Support for grieving siblings is as unique as the siblings themselves, but usually involves recognizing the relationship they had with their sibling who died, making space for and finding words for the grief they are feeling, acknowledging and celebrating the siblings as their own selves, independent from their deceased siblings, and encouraging and celebrating their accomplishments, joys, and interests. Support may also come in the form of scaffolding opportunities for ritual, honoring, and remembrance. In my virtual work with siblings, I have helped children make memory boxes, write stories, draw what Heaven looks like, write letters to their siblings, grow plants in memory of their siblings, and express their grief through creative art projects such as paper lantern making and fairy house building. Grieving siblings may also benefit from support in recognizing how each member of their family is experiencing and expressing grief differently. They need to know that they are free to be themselves and they need to know that they are not alone.

I am primarily an inpatient CLS, and thus am unable to do sibling support on a full-time basis. These visits are scheduled when I have time, and are in keeping with what the families request. I am referred for sibling support by our hospital's bereavement coordinator and social workers, as well as through my own interactions with families in our Palliative Care service. I make it clear that I am not a licensed therapist, but rather can provide a dedicated space for siblings to ask questions about what happened, talk about their sibling with someone who often knew their sibling, and/or begin to put words to the vast concept of grief through a mix of therapeutic play, age-appropriate conversations, and purposefully selected books.

Additionally, and equally important for some siblings, I can provide a space where they can play, talk about their interests, and be themselves. There are some siblings, like the aforementioned little boy, who I've spoken to only once. Others have had several sessions with me, either consecutively or during particularly charged times in their grief. I had a conversation with one child after his sister died, and again the day after her funeral, and again many months later when he was moving out of the home they had shared. There are other children with whom I've had more long-term relationships, the longest being a child I have been talking with over Zoom for over a year. Sometimes we do therapeutic activities or art, sometimes we play games, and other times he puts the iPad on the trampoline and talks about his brother as he jumps. I catch every third word as I watch the sky bounce around.

Grief cannot be cured. It cannot be fixed, or denied, or distracted. Grief can, however, be heard. It can be held. It can be pounded in to clay and played out through stuffed animals and talked about intermittently while playing Zoom Charades. Every grieving sibling can benefit from a dedicated space to express that grief using the language of their heart. I have found that the virtual platform can be a way to create that space.

"We used to go in this hammock," the little boy says.

He turns the camera so I can see.

"That's a nice hammock."

"Let's go in."

In he goes, bringing my view from the camera with him. I watch him swing back and forth.

"Wanna hear a song?" he asks.

Without waiting for an answer he starts to sing, matching his rhythm to the swinging. The song is a duet from a game they used to play. He sings both parts, letting me know which is which. He says, "I'm getting good at singing both."

Before we hang up I thank him for his song, grateful that he shared it with me and honored to have been given a brief window in to his world.

Considerations In Supporting Siblings Of Medically-Complex Children

Jessica Sturgeon, MT-BC, HPMT

Board-Certified Music Therapist

NICU Music Therapist

AccentCare; Formerly Seasons Hospice and Palliative Care

Middlebury, CT

JessicaSturgeon@accentcare.com

Often seen as the “invisible child,” siblings of children with medically-complex conditions face unique struggles as families navigate the medical paradigm. Evidence-based research indicates that there are many potential emotional implications for siblings within a family system that is experiencing the various traumas associated with illness due to factors both related and unrelated to the illness itself. Social, emotional, cognitive, spiritual, and physical considerations must all be taken into account when working with any child facing illness whether directly or indirectly.

Derek was a 16-year-old male sibling experiencing the roller coaster of changes associated with his brother's illness. As a teen, he was facing many changes in his life that attributed to a heightened stress response that was then elevated even further by the increased medical needs of his younger brother. When approached by the palliative care team, it was evident that Derek would benefit from additional individualized support as he was experiencing increased symptoms of depression, anxiety, and potential parentification by taking on additional responsibilities in caring for his family. There was fear of traumatization because of the fragility of his brother's condition due to hospitalizations and alarms that prevented him from sleeping well during the night. This often left him in a heightened state of arousal during the day at school and at home. Through the use of music therapy, he was able to explore these emotions and stressors in a creative manner while simultaneously working towards building a “tool box” of coping mechanisms to utilize as needed. Several themes arose that highlighted important considerations in caring for and working with siblings through creative intervention including the need for safety, self-expression, individualized care, and proper termination.

Safety

Promoting a sense of safety, both physically and emotionally, is a crucial first step in caring for any individual in a therapeutic context. When working with siblings specifically, it is this consideration that creates the foundation for any type of work to progress. Derek often identified feeling unsafe emotionally due to several factors both related and unrelated to his brother's medical condition. Given his age, he was experiencing rapid changes that often left him drained and uncomfortable at times. This was only exacerbated by the limited sleep he was able to receive between school, extracurricular activities, and the medical needs of his brother that often occurred during the night. His physical discomfort only heightened his emotional discomfort. This initially created a barrier in the therapist/client relationship as he was resistant to engage and displayed difficulty in focusing. In identifying that space was a method of safety and coping for him, the music therapy interventions were able to be tailored to promote just that. Indirect interventions including improvisation and song sharing/listening were offered to validate that need for space rather than relying on direct interventions such as songwriting or lyric analysis that

would put pressure on interaction rather than experience. Over time, this allowance for space created increased safety as he was able to direct when he was ready to open up about his experiences. Derek also felt compelled to take on several caregiving roles for his brother, which then began leading to parentification or taking on a “parent” role in his brother’s care. As he continued to explore his feelings creatively through music therapy, he began to feel increasingly safe in being a teenager rather than the parent and learned how to give himself permission to make mistakes and lean into the teenage experiences and reinvesting in friendships.

Self-Expression

Self-expression is a vital component of any client/therapist relationship and is often where epiphanies are hatched. This can be stunted or discouraged in siblings, however, due to the nature of care that needs to be provided to children with medically-complex conditions. Self-expression thrives in an environment in which it is positively reinforced. Unfortunately, this does not always have the potential to occur when time and attention needs to be redirected towards the illness. After creating a foundation of safety, siblings will often benefit from simply getting their own space and feeling heard. In music therapy, the concept of self-expression was reinforced with Derek as themes would arise in discussion that could then be validated through active music engagement in playing the piano or identifying a song that reflected similar sentiments. By expressing himself, Derek verbalized feeling “lighter” after sessions as he no longer had to carry the weight of his own thoughts by himself. Expressing himself also allowed for the opportunity to disarm negative/intrusive thoughts and disprove imaginary thoughts that had been weighing on him-sometimes for years. As his comfort increased and he was successful in expressing himself in music therapy, it opened the door for him to express himself and identify his needs to his family.

Individualized Care

Individualized care has become a buzzword in the medical community for good reason. Numerous quality indicators affirm that better outcomes arise from an individualized approach. This can be inclusive of goals and interventions but also speaks to the importance of holding space. Providing an individual seen as a “special person” solely for the sibling with whom to cultivate a therapeutic relationship can also assist with combating feelings of invisibility as it reinforces that they are important and worthy of their own support. When siblings are given individualized care, there is a greater potential that the sense of safety and benefits of self-expression will continue. Derek responded well to the consistency of having the same music therapist providing support as there was limited disruption in the therapeutic process. Further, it allowed there to be a continuous growth towards goals with minimal disruption. This also offered the opportunity for various approaches to be altered to best fit his needs as time progressed and as his brother’s condition changed. As Derek was able to better process his experiences and gain a sense of control over his environment, interventions and techniques were able to be altered to challenge him in new ways and help him experience new methods of coping by tapping into his existing creativity.

Proper Termination

Termination can be a difficult subject to address, but there is an inherent necessity in identifying the considerations of impact on the family system. There can be significant feelings of loss that comes from termination from the team themselves whether the patient dies, is discharged from services, or the clinician is leaving the team. Although there is no way to extinguish the feelings of loss, there are many strategies that can alleviate the anxiety associated with terminating relationships with siblings or any member of the family unit. With Derek, the most crucial step was to immediately identify and reinforce boundaries. Being a teenager, it was easy for him to begin assimilating and associating himself as a peer or friend while receiving music therapy. Given the nature of creative intervention, it is common for vulnerability to enhance feelings of closeness that can mimic friendship. In order to combat this, task-oriented interventions could be utilized to promote structure while also

highlighting the therapist/client roles without sacrificing work towards therapeutic goals. In the case of Derek, the upcoming termination as he was leaving for college became a subject that was both processed during sessions and joked about at times. This normalization of the shared experience of termination minimized any "surprises" and created an environment to prepare him rather than to revert back to avoidant behaviors. In fact, the six-month preparation and discussion allowed for special projects to be completed both collaboratively through songwriting and individually through tokens of gratitude and memories. In the case of siblings, feelings of abandonment and loneliness can be pervasive. To minimize this, proper termination is crucial to continue their development towards feeling safe and valued. In cases where termination can't be planned in advance, having appropriate follow up to terminate and establish additional supports moving forward is vital in maintaining a sense of homeostasis.

Evidence and research continue to show the necessity of support for siblings of children with medically-complex conditions. By allowing the space for the all of the aforementioned to occur in addition, there is an enhanced ability to support the family system as a whole and promote growth and healing moving forward.

Supporting The Family Including Siblings With A Brother Or Sister In The NICU During the Pandemic

Denise Morrissey Chaveriat, BS, CCLS

Child Life Specialist

Creative Arts, Therapy, and Education Department

Advocate Children's Hospital

Oak Lawn, IL

Denise.Morrissey@aah.org

COVID changed many things especially in the hospital setting and in the NICU where premature babies are cared for. Families have always needed extra support during the birth of a premature baby. When the pandemic began, families needed support more than ever. Reflecting back, there is much that was done. Our NICU's supportive team consists of two social workers, a chaplain, palliative care nurse, care coordinator nurse, child life specialist, music therapist, and a therapeutic listening nurse. Since parents could not gather in a community setting anymore, our team supported parents at the patient's bedside.

Our unit is all private rooms which was ideal for the changes that developed. Our parents were now alone, placed in unfamiliar environment, and vulnerable from having an unexpected early birth. Our supportive team collaborated to aid our families. We began meeting weekly to best use resources. Our team created a letter to families which provided each associate's photo and a simple statement with scope of services. Our social worker expanded their assessment tool asking about food insecurities, family resources, transportation needs, and internet insecurities.

To address the issues, we began partnering with current and new organizations. We were able to provide "grab and go" snack bags in our family lounge, along with a new packet of resources for families. We also created new virtual parent groups. Parents were stressed and needed new ways to receive information, so we implemented a "welcome orientation class" online that allowed parents to learn more about the NICU environment and how they could participate daily. The admission folder also included a link to the unit tour video. I provided additional books for families to read to babies focusing on themes of love and inclusive, and books in various languages. I created a monthly seasonal craft kit to aid in creating keepsakes. I provided coping kits for parents which included stress ball, paper, pens, coloring pencils, coloring sheets, and narrative journal activities along with milestone photo sharing activity. I placed craft supplies to aid in easy access for staff to create name banners and milestone keepsakes, thereby personalizing baby's space. All these simple things gave much comfort to the families during this difficult time.

Those patients that had older siblings needed a different type of support. Instead of attending school with their older siblings, students were learning via online school while their parents had a baby in the NICU. Everyone had new routines at home, and new concerns arose from social isolation. While in the hospital or over the phone, I spoke with parents reviewing resources our team created for any hospitalized child and their siblings. We discussed ways to support their children including establishing routines and expectations for the following day, and learning what works for their household. I also created sibling packets that included "My Sibling Scrapbook"

an activity book for siblings of a NICU patient. Created by a retired CCLS, we also have them printed in five languages. In addition, I included a NICU sticker scene, seasonal craft kits, a bracelet, "Super Sibling," and "All about me" poster. All of these items could aid in personalizing each patient's room while informing staff about the family and each sibling.

I also sent home board games and family kits to encourage family game night and family time. These kits had themes of family and love. Parents were encouraged to create a family canvas, tracing each person's hands on paper/canvas. Another family kit included decorating wooden hearts for each family member and placing a set at the hospital and one in the home.

Parents are always encouraged to continue to keep siblings informed about changes in their day, updates on baby, and keep promoting bonding with their new sibling when possible. Parents and siblings were inspired to schedule a virtual visit with their baby. By utilizing the hospital's virtual visiting platform or personal devices like facetime or Zoom, parents could visit with their baby while at the hospital and at the same time including siblings or extended family. Parents could also enroll in a photo sharing program to receive photos of the patient. Our IT department is currently looking at enhancing these programs.

For extreme situations, parents could allow siblings to come to meet and say goodbye to their baby brother or baby sister. This involved figuring out a schedule with the family to best meet the needs of all involved. Siblings along with their parents meet with CCLS before visiting to prepare siblings using simple informational books CCLS created. CCLS was with each family during each visit to aid in creating memories and to offer support as needed.

Protecting neurological development is always at the forefront of anyone working in the NICU. Families and staff continued to need to mask even as the babies grew older. Our hospital recognized the emotional and developmental needs of our older babies. The hospital purchased clear masks for staff and families of older patients. This is so important as babies bond with their caregiver's facial interactions.

As I reflect on so many changes in the hospital, one thing remains the same: When you care for patients in the NICU, you realize the necessity of supporting the parents and siblings as well.

A Sibling Grief And Bereavement Toolkit

Allison Fuson, MS

Pittsburgh, PA

allisonfuson@gmail.com

Over the 2021-2022 academic year, I collaborated with the community organization Pediatric Palliative Care Coalition (PPCC) and completed a capstone project for the organization. The Pediatric Palliative Care Coalition is a non-profit organization located in Fox Chapel, Pennsylvania, that provides support and resources for families and medical professionals who care for children with life-limiting illnesses through various outlets, including education, information, and advocacy. During a needs assessment interview with the PPCC's Executive Director, Betsy Hawley, the need for a more direct connection with families was identified. Therefore, the capstone project design sought to provide another resource for the PPCC website that both families and medical professionals could access at any time. This capstone project design involved developing a Sibling Grief and Bereavement Toolkit as an additional resource for the PPCC's website. In addition, the toolkit's goal is to provide an array of information and resources for anyone working with or supporting a bereaved school-aged child after the death of a sibling.

Grief is an individual process that can be experienced at any developmental stage. People can undergo the grieving process at various points in their lives as their emotional and cognitive abilities change, whereby they experience multiple emotions and reactions to the loss. Furthermore, experiencing grief during childhood can affect children differently than those who face grief as adults. Therefore, through providing this newly-developed resource, family members and other individuals working with bereaved siblings can access this toolkit to understand the grief process school-aged children can experience after the death of a sibling and provide ongoing support.

Foundations

Research has shown that children can experience various emotions after the loss of a sibling, which can include anxiety, guilt, depression, anger, and fear (Akard et al., 2019; Brooten & Youngblut, 2017; Roche et al., 2016). In addition to these emotions, children also experience many reactions, one of which includes children reflecting on the time with their sibling before death. With this reflection, research has shown that children think about what they wish they had and hadn't done with their sibling when they were alive (Brooten & Youngblut, 2017; Youngblut & Brooten, 2021). For example, children wished they had spent more time or treated their siblings better than they did. Therefore, these factors show the complexity of grief for children.

Furthermore, research has looked at the benefits of therapeutic activities for children. For example, therapeutic activities can provide creative outlets for children who have difficulty verbally stating the emotions they are experiencing in terms of their grief process. As a result, therapeutic activities can show benefits in understanding the child's grieving process and coping methods with sibling death (Stutey et al., 2016). Therefore, giving children the chance to express themselves in various ways through selected activities can help them cope with a sibling's death in different ways.

Partnering with the PPCC led to the creation of a resource that provides information not only about school-aged children's grief after sibling death but also therapeutic activities that could be beneficial in helping children process and understand their emotions. While the PPCC provides beneficial resources for families and medical professionals, the need to increase the resources directly available for families was recognized through the needs assessment. Therefore, this capstone led to developing a Sibling Grief and Bereavement Toolkit to provide a beneficial and informative resource to help families support and understand children's grief after sibling death.

Development of the Toolkit

The development of this project design involved researching information about school-aged children's grief following the death of a sibling. With this research gathered, a decision was made to create the Sibling Grief and Bereavement Toolkit in four sections: school-aged children's grief reactions related to death; emotional experiences related to death; therapeutic activities; and additional resources.

The first two sections included information and research about school-age children's developmental reactions to death and their emotional experience to understand what children go through after the death of a sibling. The third section provided five therapeutic activities specifically chosen to help children process their grief. The development of these activities was guided by research that supported expressive activities provided through both a non-verbal and verbal format, as well as creative outlets for children to show how they are feeling. In addition, each therapeutic activity was uniformly formatted to include materials needed, directions, and information about the psychosocial benefits of the activity and any adaptations (i.e., adapting the activity for older children). An example of one of the therapeutic activities developed is the Role-Playing Activity. This activity was developed to provide the opportunity for families or professionals to have open conversations with children after the death of a sibling. These conversations include discussing any worries, fears, or questions caregivers and children have about returning to activities and settings. Through these conversations, families can have open discussions and address different aspects of worries or fears together and become more comfortable responding to questions that could emerge. In addition, these conversations can provide a beneficial outlet for children's grief and coping processes. Finally, the last section of the toolkit provided additional resources, such as books for children and teens, beneficial websites and organizations to explore, research articles pertaining to the toolkit's topic, and additional resources for parents.

The Inspiration Behind the Capstone Project Design

The inspiration for this project design involved working with the PPCC organization and personally experiencing the death of a sibling during the school-age years. As a seven-year-old child, I struggled with the death of my baby sister and had a difficult time understanding my grief and emotional experience. However, with support from my family and community organizations, I learned how to cope with my sister's death throughout the years.

When having the opportunity to complete a capstone project during the second year of my master's degree in Applied Developmental Psychology at the University of Pittsburgh, I knew that I wanted to complete a project that would help families and siblings who were grieving the death of a loved one. The development of this capstone project design was influenced by the needs of the organization and my initial idea for the project. Therefore, through the needs assessment and my experience, the Sibling Grief and Bereavement Toolkit was created and completed to help families and other individuals supporting children grieving the death of a sibling.

Conclusion

With the completion of this project, my goal is for the Sibling Grief and Bereavement Toolkit to be an effective and valuable resource that provides an understanding of school-aged children's grief experiences after the death of a sibling. In addition, this toolkit was developed to be a supportive and beneficial resource for families, siblings, and professionals to utilize.

This resource will be available on the PPCC's website in August 2022. Please see the link attached that will direct you to the Sibling Grief and Bereavement Toolkit located on the PPCC's website: [PPCC Sibling Grief and Bereavement Toolkit](#).

References

- Akard, T. F., Skeens, M. A., Fortney, C. A., Dietrich, M. S., Gilmer, M. J., Vannatta, K., Barrera, M., Davies, B., Wray, S., & Gerhardt, C. A. (2019). Changes in siblings over time after the death of a brother or sister from cancer. *Cancer Nursing, 42*(1), E20–E27. <https://doi.org/10.1097/ncc.0000000000000573>
- Brooten, D., & Youngblut, J. M. (2017). School aged children's experiences 7 and 13 months following a sibling's death. *Journal of Child and Family Studies, 26*(4), 1112–1123. <https://doi.org/10.1007/s10826-016-0647-7>
- Roche, R. M., Brooten, D., & Youngblut, J. M. (2016). Parent & child perceptions of child health after sibling death. *International Journal of Nursing & Clinical Practice, 3*(185), 2–7. <https://doi.org/10.15344/2394-4978/2016/185>
- Stutey, D. M., Helm, H. M., LoSasso, H., & Kreider, H. D. (2016). Play therapy and photo-elicitation: A narrative examination of children's grief. *International Journal of Play Therapy, 25*(3), 154–165. <https://doi.org/10.1037/a0039956>
- Youngblut, J. M., & Brooten, D. (2021). What children wished they had/had not done and their coping in the first thirteen months after their sibling's neonatal/pediatric intensive care unit/emergency department death. *Journal of Palliative Medicine, 24*(2), 226–232. <https://doi.org/10.1089/jpm.2019.0538>

Additional Resources

- Boyd Webb, N. (2011). Play therapy for bereaved children: Adapting strategies to community, school, and home settings. *School Psychology International, 32*(2), 132–143. <https://doi.org/10.1177/0143034311400832>
- Coalition to Support Grieving Students. (2016). *Supporting your child: After the death of a family member or friend*. https://grievingstudents.org/wp-content/uploads/2016/05/Supporting-Your-Child_Final-For-Distribution1.pdf
- Courageous Parents Network. (2021). *What is anticipatory grief?* <https://courageousparentsnetwork.org/guides/coping-with-anticipatory-grief>
- Dougy Center. (2022). *Dougy center*. <https://www.dougy.org/>
- Heal Grief. (2018). *Grieving the death of a sibling*. <https://healgrief.org/grieving-the-death-of-a-sibling/>
- Jonas-Simpson, C., Steele, R., Granek, L., Davies, B., & O'Leary, J. (2015). Always with me: Understanding experiences of bereaved children whose baby sibling died. *Death Studies, 39*(4), 242–251. <https://doi.org/10.1080/07481187.2014.991954>

National Alliance for Children's Grief. (2021). *Home*. <https://childrengrieve.org/>

New Zealand Paediatric Palliative Care Clinical Network. (2021). *Bereavement reactions of children & young people by age group*. <https://www.kidshealth.org.nz/bereavement-reactions-children-young-people-age-group>

OUR HOUSE Grief Support Center. (2018). *Death of a sibling*. <https://www.ourhouse-grief.org/grief-pages/grieving-adults/death-of-a-sibling/>

Roche, R., Youngblut, J. M., & Brooten, D. A. (2020). Parent and child perceptions of the child's health at 2, 4, 6, and 13 months after sibling intensive care or emergency department death. *Journal of the American Association of Nurse Practitioners*, 33(10), 793–801. <https://doi.org/10.1097/jxx.0000000000000429>

Salek, E., & Ginsburg, K. (2014). *How children understand death & what you should say*. American Academy of Pediatrics. <https://www.healthychildren.org/English/healthy-living/emotional-wellness/Building-Resilience/Pages/How-Children-Understand-Death-What-You-Should-Say.aspx>

Schonfeld, D. J., & Quackenbush, M. (2009). *After a loved one dies: How children grieve and how parents and other adults can support them*. New York Life Foundation. <https://portal.ct.gov/-/media/SDE/Digest/2017-18/New-York-Life-Foundation-Bereavement-Guide---After-a-Loved-One-Dies.pdf>

Sesame Street in Communities. (2021). *Helping kids grieve*. Sesame Workshop. <https://sesamestreetincommunities.org/topics/grief/>

Stanford Children's Health. (2022). *A child's concept of death*. <https://www.stanfordchildrens.org/en/topic/default?id=a-childs-concept-of-death-90-P03044>

St. Jude Children's Research Hospital. (2022). *Helping your school-age child cope with death*. <https://www.stjude.org/treatment/patient-resources/caregiver-resources/patient-family-education-sheets/child-life/helping-school-age-child-cope-with-death.html>

Team Scary Mommy. (2021). *15 meaningful grief and loss activities to help kids cope with death*. Scary Mommy. <https://www.scarymommy.com/grief-activities-for-kids/>

The Compassionate Friends. (2017). *Family support*. Compassionate Friends. <https://www.compassionatefriends.org/find-support/family-support/>

The Highmark Caring Foundation. (2022). *Highmark caring place: A center for grieving children, adolescents and their families*. <https://www.highmarkcaringplace.com/cp2/index.shtml>

The National Children Traumatic Stress Network. (2009). *Sibling death and childhood traumatic grief: Information for families*. http://centerforchildwelfare.org/kb/TraumaInformedCare/Sibling_Loss_Final.pdf

UC Davis Health Children's Hospital. (2022). *Activities for grieving children and families*. https://health.ucdavis.edu/children/clinical_services/child_life_program/bereavement-activities.html

UPMC Children's Hospital of Pittsburgh. (2022). *Camp Wakchazi: Sibling bereavement program*. UPMC. <https://www.chp.edu/our-services/supportive-care/camp-wakchazi#:~:text=Camp%20Wakchazi%20is%20an%20initiative,in%20a%20safe%2C%20supportive%20environment>

UPMC Children's Hospital of Pittsburgh. (2022). *Resources*. UPMC. <https://www.chp.edu/our-services/supportive-care/resources>

Readers' Corner

Suzanne S. Toce, MD, FAAP

Retired Neonatologist

Departments of Pediatrics and Medical Humanities

Gundersen Health System

La Crosse, WI

tocess@gmail.com

Guidance for Pediatric End-of-Life Care. Linebarger JS, Johnson V, Boss RD. Pediatrics (2022) 149 (5): e2022057011. <https://publications.aap.org/pediatrics/article/149/5/e2022057011/186860/Guidance-for-Pediatric-End-of-Life-Care?autologincheck=redirected> (free open access article)

Summary: Acknowledging that ~45,000 children from birth to age 19 years die yearly, these authors, on behalf of the American Academy of Pediatrics Section on Hospice and Palliative Medicine, provide practical information and guidance for health care providers at the community through tertiary care levels in caring for dying children and their families.

Who: will benefit from this guidance? Health care providers caring for dying children/adolescents at all levels and from all disciplines will find this information explicit, necessary, and comprehensive.

What issues are addressed?

- Background information concerning childhood deaths including demographics, trajectory, location of care, and disparities in care.
- The basics of end-of-life management
 - The central role of the pediatric palliative care team involvement in the care of dying children is emphasized. This team is also skilled in addressing the communication needs of the child and family.
 - Shared decision making (inclusive of the child/adolescent as appropriate) and advanced care planning are reviewed. Triggers for initiating or reviewing the advanced care plan are delineated. Formalize and document goals of care. Guidance is offered for timing of shifting to a comfort focused approach.
 - Hoped for location of death is discussed.
 - Code status options are reviewed and preference documented.
- Planning for care as death nears
 - Address issues of nutrition and hydration.
 - Inform parents about the dying process and help them prepare. Inquire about their concerns and worries. Address uncertainties.
 - Work towards achieving the preferred site of death. Plan for transport if needed for moving the child to preferred site of death. Transport via ambulance to home for compassionate extubation is challenging but is preferred by some families. Consider a hospice facility if death at home is not feasible.
 - Emphasize the role of the interdisciplinary team.

■ Care in the final days including anticipatory guidance concerning the dying process

- Discontinue life-sustaining medical treatments that are not of benefit and are prolonging dying. Rather than "withdrawing support" or "stopping care," language should focus on what can be done to optimize comfort.
- Address hydration and nutrition issues.
 - Decisions withdrawing/withholding artificial hydration are ethically equivalent to other medical treatment decisions.
- Prepare the family for the dying process
 - Review the likely process, including uncertainties
 - Address concerns about pain and other symptoms. There is a very nice table addressing common signs and symptoms naturally occurring at end of life.
 - Adjust medications as needed to address symptoms
- Seek preferences concerning tissue and organ donation.

■ After death

- Death is declared when the clinician verifies absence of heart rate and respirations. Time of death is documented on the death certificate.
- Potential benefits of a partial or full autopsy are reviewed with the parents and preferences documented and written consent obtained as appropriate. Any autopsy results should be shared with the family when available.
- Support memory making, time with the child, bathing, dressing, etc., as desired.
- Have a team member assigned to assist in post mortem care such as contacting the funeral home (as desired), gathering belongings, leaving the location of death, and notifying the care team.
- Plan follow up care including appointment to review autopsy report, attending the funeral/memorial, and assuring letters of condolence.
- Debrief the staff
- Ensure bereavement support for the extended family. Support may also be needed for community members and in schools.

Where can this process be actualized? In most cases, the goals of care can be met regardless of setting including home, hospice, and hospital.

When should this process be initiated? Communication strategies, decisional support, advance care planning, psychosocial and spiritual support, and support of logistics should be initiated soon after diagnosis of the child's potentially life-limiting condition. As death of the child/adolescent becomes more likely, the specific components relating to the dying process should be emphasized.

Items of Interest!

In each issue of our Pediatric E-journal, we offer additional items of interest.

1. NHPCO Palliative Care Online Resources:

NHPCO has a variety of pediatric hospice and palliative care resources available at www.nhpc.org/pediatrics. Also, more palliative care resources are available at www.nhpc.org/palliativecare, including:

- Community-Based Palliative Care
- Legal and Regulatory Resources
- Webinars and Courses
- Plus, more for NHPCO members

Palliative Care Programs and Professionals

Founded in 1978, National Hospice and Palliative Care Organization (NHPCO) is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families. **Join NHPCO Today!**

[Individual Palliative Care Membership](#)

[Palliative Care Group Application](#) — Save by registering your entire team

2. **Optum Hospice Annual Conference: The wait is over!** Optum Hospice Pharmacy Services is excited to announce that [registration is now open](#) for its October 7 annual conference.

This **FREE** one-day virtual conference will provide valuable education to all hospice clinicians. Keynote speakers will open and close the conference along with additional hospice-focused sessions covering adult medication management, pediatrics, and wound care.

3. **Our Bereavement Issue # 67 published May 2022, was published on the Dougy Center Website!** They have also posted a white paper and a [Call to Action – Becoming Grief Informed!](#)

4. Have you seen Unseen? An award-winning documentary, **Unseen – How we're failing parent caregivers & Why it matters.**

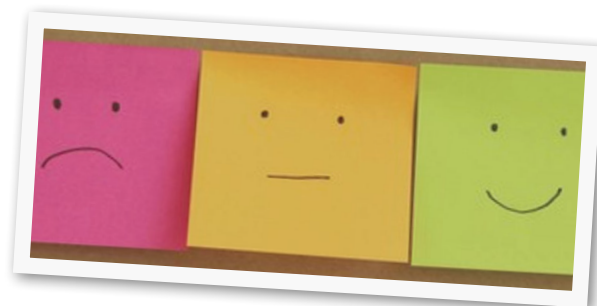
5. The Pediatric Palliative Care Coalition of Pennsylvania (PPCC) has made a new resource available – a Sibling Grief and Bereavement Toolkit. This Toolkit has been developed to address the needs and concerns of children and teens who have experienced the death of their sibling with medical complexities. **Please see the associated article in this edition!** Below is a link to the toolkit and one of the activities – “Make a Feelings Chart”.

[View the PPCC Sibling Grief and Bereavement Toolkit](#)

Toolkit Activity

For children who are grieving the loss of their siblings, returning to school can be a difficult transition. Check out this month’s highlighted activity from the toolkit that may help children and teens in the upcoming school year.

Make a Feelings Chart by [downloading](#) the activity. PPCC invites you to share this information with parents, caregivers, medical professionals, providers, therapists, etc.



6. Pediatric Hospice and Palliative Care Resources:

■ **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. www.caringinfo.org

■ [NHPCO’s Palliative Care Resource Series](#) includes pediatric palliative resources like:

- Communication Between Parents and Health Care Professionals Enhances
- Satisfaction Among Parents of the Children with Severe Spinal Muscular
- Atrophy
- Consideration for Complex Pediatric Palliative Care Discharges
- Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and Hospice Care
- Nonpharmacological Pain Management for Children
- Sibling Grief
- Pediatric Pain Management Strategies
- Communicating with a Child Experiencing the Death of a Loved One: Developmental Considerations
- In an effort to standardize the medication coverage process for children receiving concurrent care, the NHPCO Pediatric Advisory Council developed a new resource for providers titled **Determination of Hospice Medication Coverage in CHILDREN**.

7. Trends in Pediatric Palliative Care Research

Every month, PedPalASCNET collects new pediatric palliative care research. For past lists visit [their blog](#), [browse in their library](#), or join the [Zotero group](#). [View the New Citation List in their library](#).

8. JustSibs

[JustSibs](#) is an interactive, digital experience designed by [Ryan's Case for Smiles](#) to help teens and pre-teens (ages 11-16) navigate and cope with the many challenges that come with having a sibling with an illness or injury. Through visual storytelling and supportive activities, kids are given a safe space to explore, and learn to manage, a wide variety of feelings that they may face – plus have a little fun while they're at it!"

In addition, we have a few other sibling focused resources that might be useful to your organization or staff. We provide [sibling focused information and tips](#), including forms to help communicate with [schools](#) and [alternative caretakers](#), on our caregiver focused site CopingSpace. And I recently recorded a [podcast on the sibling experience](#) and our resources for families.

9. SibShops, a project of the Sibling Support Project.

The [Sibling Support Project](#), "the first national program in the U.S. dedicated entirely to recognizing and promoting the important roles that siblings play in their families and communities and to creating opportunities for brothers and sisters of all ages to receive the information and resources they need to support their families and themselves." [Sibshops](#) provide young brothers and sisters with peer support and information in a lively, recreational setting. The Sibshop curriculum is used throughout the United States and Canada and in Hong Kong, Japan, Mexico, New Zealand, Argentina, Ecuador, Iceland, Ireland, England, Italy, Malta, Singapore, and Turkey. Find a location near you on their website.

10. The National Alliance for Children's Grief has many resources and information on their [website](#) that may be of interest.

11. Subjects and Contributors for Future Issues of This E-Journal

Our future issues will be focused on the following topics. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy at Christy.Torkildson@gcu.edu or Suzanne Toce at tocess@gmail.com.

Issue Topics: 2022 (Note: Subject to Change at Work Group's Discretion)

- Issue #69: PPC in the Community, submissions due 8/2022; Publication November 2022

Issue Topics: 2023 (Note: Subject to Change at Work Group's Discretion)

- Issue #70: Perinatal/Neonatal, submissions due 12/2022; Publication February 2023
- Issue #71: Standards, submissions due 02/2023; Publication May 2023

Please note that archived issues are available as a community-service by NHPCO and can be found at www.nhpc.org/pediatrics.



NHPCO

National Hospice and Palliative
Care Organization

NHPCO

1731 King Street
Alexandria, VA 22314

tel. 703.837.1500 | nhpco.org