Welcome to the 47th issue of the ChiPPS E-Journal. This issue of our E-Journal offers a collection of articles that explore selected issues related to delivering care to siblings and grandparents, both of whom are often described as “forgotten grievers.” This issue explores needs of siblings and grandparents, while also offering suggestions concerning their care as an important aspect of providing pediatric palliative/hospice care. We appreciate that a single issue on this subject will not do complete justice to this subject area and we would especially have liked to be able to give more attention to grandparents, but we hope that the articles in this issue will spur increased awareness and discussion of these subjects. We welcome communications from anyone who has more to offer on these subjects.

This E-Journal is produced by ChiPPS (the Children’s Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO’s E-Journal Work Group, chaired by Christy Torkildson. Archived issues of this publication are available at www.nhpco.org/pediatrics.

Comments about the activities of ChiPPS, its E-Journal Work Group, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Please contact Christy at christytork@gmail.com.

Produced by the ChiPPS E-Journal Work Group

- Donna Armstrong, MSW, CSW, Instructor, College of Social Work, University of Kentucky, Lexington, KY
- Charles A. Corr, PhD, Member, Board of Directors, Suncoast Hospice Institute, Pinellas County, FL; Senior Editor
- Ann Fitzsimons, BS, MBA, Executive Director, here4U, Inc., Farmington Hills, MI
- Erin Gaab, PhD, Postdoctoral Scholar, University of California Merced, Health Sciences Research Institute, Merced, CA
- Betsy Hawley, MA, Executive Director, Pediatric Palliative Care Coalition, Pittsburgh, PA
- Maureen Horgan, LICSW, ACHP-SW, Executive Director, Gentiva Hospice, Seattle, WA
- Melissa Hunt, PharmD, Pediatric Clinical Pharmacist, HospiScript, an Optum Company, Montgomery, AL
- Nathan Ionascu, MD, Bioethics Consultant, Westchester End-of-Life Coalition, Westchester County, NY
- Randy Johnson, MDiv, Chaplain, Pikesville Hospital, Pikesville, KY
- Kelly Cronin Komatz, MD, MPH, FAAP, FAAHPM, Clinical Medical Director, Community PedsCare Program, Medical Director, Pain and Palliative Care, Wolfson Children’s Hospital and Wolfson Center for the Medically Complex Child at University of Florida, Jacksonville, FL
- Rachel Levi, PhD, Licensed Psychologist, Private Practice, Oakland, CA
- Suzanne Toce, MD, Retired Neonatologist, Gundersen Lutheran Health System, La Crosse, WI
- Rebecca Simonitsch, MS, MAEd, CT, CCLS, Advance Care Planning Coordinator, Cottage Health, Santa Barbara, CA; UCSB Extension, Instructor
- Christy Torkildson, RN, PHN, MSN, PhD, Chief Academic Officer, Unitek College, Fremont, CA; Chair

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Issue #47: Care of Siblings and Grandparents

(Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.)

Scott Newport’s Comfort Carts  
This article shares with readers pictures of Scott’s work in constructing “Comfort Carts.” The article also asks: what siblings and grandparents might contribute to such comfort carts; what contributions could be made to such comfort carts to support siblings or grandparents; and/or how readers might use their own skills to help in the care of children who are ill, dying, or deceased and their families.

The Death of My Sister  
Mackenzie Elder
The author writes as a 19-year-old college student whose younger sister died. She describes the blow of learning that Maggie had a tumor on her pelvis, the helpless feelings she endured during Maggie’s treatments, and her grief after Maggie’s death. Mackenzie offers two important observations: (1) people often make the mistake of thinking that there is always someone who gets it, but there isn’t always someone who understands. It takes time. Grief always takes time; and (2) a family who grieves together, stays together. It seems impossible to watch the people you love go through the hardest time in their lives, but it’s worth it to get to other side together.

What about Me?; Addressing the Grief and Bereavement Needs of Siblings  
Danielle Jonas, MSW, Caitlin Scanlon, MSW, Susan Gorry, CCLS, & Jori F. Bogetz, MD
The authors use case examples to: “(1) review how the death and prolonged illness of a sibling impacts children at various ages; (2) identify interventions that can be used with grieving siblings; and (3) describe the roles and responsibilities of pediatric providers in supporting grieving children and their families.” They offer the following conclusion: “Attending the needs of siblings who are grieving during the illness trajectory, as well as to bereaved siblings after the loss of a child, are critical aspects in providing true family-centered care. These losses stay with children throughout their lifetime. There is so much that can be done to foster a sense of hope and meaning during this process that can later impact a child’s grief. Fortunately, there are many trained professionals who can share in this important work.”

What Siblings Would Like Parents and Service Providers to Know  
Don Meyer
Because typically-developing brothers and sisters “will be in the lives of family members with special needs longer than anyone” and because “brothers and sisters share many of the concerns that parents of children with special needs experience . . . [and] also face issues that are uniquely theirs,” this article offers 20 recommendations for parents and service providers from the Sibling Support Project.

If Only  
Jennifer Holler, LCSW, ACHP-SW
The author describes the development of a teen grief support program in a small community after a 16-year-old boy died from an accidental gunshot wound. She is candid about her hesitations in leading this group, what she learned from its members, and how a writing assignment demonstrated that members of the group “transitioned from a place of hopelessness to hope.”
“Can You Play With Me?” Using Play to Support the Siblings of Pediatric Hospice Patients

Lenze Ramage, CCLS, & Stephanie Lamy Mishoe, MEd, CCLS

In this article, the authors argue that many siblings of seriously-ill and dying children may have limited verbal skills to cope with the strong emotions they are experiencing, may be unsure how they are supposed to react, and may be afraid how others around them will react. For such siblings, the natural art of play may provide an outlet for self-expression, a way to build memories together, and a way to regain independence and control in their lives.

The Forgotten Grievers

Magellan Taylor, MA, CCLS, GC-C

The author is a child life specialist who describes working with a child with a non-curable brain tumor. Here she describes her interventions with the child, classmates, their parents, and school staff. As she says, Morgan needed her friends and they needed help to interact constructively with Morgan both before and after her death.

The Bus Stop Club, Inc.

Brian Sheridan, M.D.

The Bus Stop Club program offers free, monthly, two-hour sessions at eight different locations in the Albany, NY, area, along with Family Events, for siblings of children with chronic illness or developmental, physical, or intellectual disabilities. The goal of the program is to “provide support through preventative intervention mechanisms designed to enhance sibling adaptation and enable them to remain emotionally healthy and well-adjusted in order to cope with one of the worst hardships any member of the family can endure.”

Books & Resources for Siblings with a Special Healthcare Needs Brother or Sister or Who Has Had a Sibling Die

Compiled by Ann Fitzsimons, BS, MBA, Rachel Levy, PhD., & Jennifer Mangers, MS, CCLS

This extensive bibliography with brief descriptions of each book includes books for siblings (divided into titles for younger and older readers, as well as those for all ages), plus websites for siblings and websites for purchasing sibling supportive care books or for finding other books of interest.

The Lives and Deaths of Two Children: The Grandparents’ Role

Gay Lord

The author is the grandmother of two children born individually to her own twin sons. She describes here early diagnostic difficulties, eventual confirmation of the diagnosis of Tay-Sachs disease, and efforts by all of the children’s parents and grandparents to make the lives of the children as full as possible. She also points out the difficulties for a grandparent in seeing one’s own adult children suffer in ways grandparents cannot fix. As she writes, “We thought that the most important things we could do for our children, and for ourselves, were to find all the occasions we could to comfort, hold, and care for the babies, to know their love, and to recognize them as individuals” and concludes “These children gave us so much more than we could give them.”

Sudden Infant Death Syndrome: For Grandparents . . . A “Double Grief”

First Candle/SIDS Alliance

This article, reprinted here by permission, describes the complexities of grief experienced by grandparents. It seeks to normalize grief reactions over what a grandparent might have done or not done. It also provides information specific to encounters with SIDS and helping in such situations.
Commentary by Colleen Pawliuk, Librarian for PedPalASCNET

We inaugurate a new feature in this issue by reprinting a citation list generated monthly by PedPalASCNET to collect new articles in pediatric palliative care research. This list of articles should be self-explanatory, but its origin and goals are explained in the Commentary at the end of this article by Colleen Pawliuk, Librarian for PedPALASCNET.

ADDITIONAL NOTES

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.

Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its E-Journal Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work. If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to CHIPPS2@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the ChiPPS Web page at www.nhpco.org/pediatrics for previous issues of this E-Journal, additional materials, and other resources of interest.

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As faithful readers of this E-Journal know, we affectionately refer to Scott Newport as our “resident poet.” We do so because Scott often contributes a reflective poem to many of our issues. He has also contributed an occasional essay, typically reflecting his thoughts about the life and death of his son, Evan, or about some of the many parents and children whom he has tried to support in what he has called “the most dreadful time of their lives.”

But Scott isn’t just a writer. He also works with his hands and one of the most interesting of his recent projects is his “comfort carts.” We thought it would be interesting to share pictures of Scott and his comfort carts with our readers, partly as our way of applauding Scott in this good work and partly as a way of suggesting how they could be used to support not just parents and ill children, but also siblings and grandparents (our main topics in this issue). As you look at the following pictures, please think about how comfort carts like these could include materials for siblings and for grandparents. Think also about how siblings and grandparents could contribute to these comfort carts. If you are a sibling or a grandparent, what might you wish to add to one of these comfort carts? How could you help other members of your family through the things you put in the cart?

Also, while many of us do not have Scott’s manual skills and might think that constructing a comfort cart like those he has made is beyond our abilities, perhaps we could reflect on the skills we do have and consider how we could employ those skills to help families with an ill, dying, or deceased child, as well as the siblings and grandparents who are important parts of those families.

If you have suggestions for contributions you might want to make to a comfort cart or if you have ideas about other things that could be done to help in this way, please share them with us and we will, in turn, share them with readers in a future issue. Suggestions can be sent to Christy Torkildson (Christytork@gmail.com), Ann Fitzsimons (ann@here4U.net), or Chuck Corr (ccorr32@tampabay.rr.com).
The first picture in this article is of Scott with a comfort cart in progress. The remaining pictures show a comfort cart that Scott was commissioned to make for the palliative care program at Akron Children’s Hospital (those pictured include Scott, the funding family on his right, and Dr. Sarah Friebert and members of her staff).
I was asked to write about what it is like to lose a sister. I will happily tell you what it felt like to be torn away from my best friend before I was ready, but I will not speak to you of “loss.” I didn’t lose Maggie. She has not been misplaced. I will tell you my story, but first you must understand that she is not lost. She is gone. Poof. One day we will all be gone, Maggie’s time just happened to be sooner than most.

My name is Mackenzie Elder. I am 19 years old. I attend the University of Pittsburgh. I am about to finish my freshman year. All you really need to know about me is that I am a big sister to an amazing girl named Maggie. She was kind, smart, funny, and a pain, but she was mine. A little over five and a half years ago my life was turned upside down. My whole family had been training for a 5k and every time my little sister ran she would have pain in one of her legs. After a pediatrician, chiropractors, a physical therapist, and a sports medicine doctor, Maggie finally got an MRI. That’s when they found the tumor. It was very large and situated on her pelvis.

I remember being in the kitchen when Maggie and my mom walked into the house. Mom went straight upstairs and suddenly it was just Maggie and me. I was about to ask her how the appointment went when she looked at me. Maggie had this way about her, one look was all it took to know exactly what she was feeling. This look was different. It was special. I had never seen it before. I had never seen it before. Any thoughts that may have been bouncing around in my head left and I stood, quietly, waiting for her to tell me what was going on. She gave me another glance and then she said, “I have a tumor.” She said nothing else. Just, “I have a tumor.”

I didn’t know what to say. Was this some kind of sick joke? So I looked at her. I watched as she flicked her eyes left then right, shuffled her feet, and played with her hands. Maggie couldn’t lie, and physically it appeared as if she was doing just that; but as I continued to watch she dropped her hands, planted her feet, and starred me straight in the eye. She didn’t falter. Finally, I reached my hands out and pulled her in for a rare hug.

It wasn’t until later, in the safety of my own room, that I got to process what she had said. I didn’t know, then, what having a tumor meant. I didn’t know, then, that the sister who had always been by my side was about to be whisked away on hospital trips. I didn’t know that every two weeks she would be at the hospital and I would be home. I didn’t know about the medication, the scans, the shots, the Chemo. That night in my room all I knew was the crushing weight on my chest. That’s what it felt like to be told that your sister has cancer. It felt like someone was sitting on my chest slowly crushing the breath out of me.

That was the first of many times that I would feel helpless. In the following eight months my family went through countless ups and downs. We watched as Maggie, the girl who ran everywhere, got stuck in a wheelchair unable to walk let alone run. We would get to watch as she stood up and learned how to take a few steps on her own. We watched her beautiful hair start to fall out. We watched her get her head shaved because the itch was just too much. We watched her laugh. We watched her cry. We watched her smile. We watched her eat. We watched her sleep. We watched every single breath she took. We watched her as she stopped talking. We watched as she became unresponsive. We watched her take her last breath. We watched, and took part in, her funeral; and then we watched each other as we grieved for the next year.

The end of that first year found us back in the hospital that had once been our second home, for the first time. Four years ago I sat in a chair at the memorial service that goes on every six months. While I was there I got a name tag, I listened to speakers who seemed to go on for forever, I watched the slideshow...
that made me want to cry, I heard musicians play beautifully, and I had a terrible attitude about all of it. Four years ago sitting in that chair was the last place I wanted to be.

Going back to the hospital was the last of my list of “firsts” without my sister by my side. My long list of firsts began on February 23, 2012. My first full day without Maggie (she died on February 22, 2012). Then there was St. Patrick’s Day, which I had never cared about before, but March 17th came and went, taking with it people dressed in green and my second first without Maggie. My next first was the Easter season. That was very hard. Easter has always been a very important holiday to my family because we were, and I still am, Catholic. Then came Mother’s Day and Father’s Day. I have never felt worse for my mom and step dad than on those days. Then my birthday, Thanksgiving, Christmas, New Year’s. It was all awful.

People who haven’t experienced this grief don’t understand we don’t just grieve on the big days. Holidays and birthdays are hard, yes, but I began grieving on that day Maggie told me she had a tumor and I haven’t stopped since. My worst day during that first year wasn’t a holiday or a birthday. It wasn’t a special day at all. It was Wednesday May 16, 2013, at 3:00 in the morning. The anniversary had come and gone, my firsts were over, and I woke up from a nightmare. I couldn’t fall back asleep so I stared through the dark at the very bare ceiling. Staring at that ceiling it hit me that my little sister was gone. I wasn’t going to see her again until I died and, hopefully, joined her in Heaven. That was the first time that I really cried for my sister. I cried for what felt like hours. I cried for my mom, for my dad, for my step mom and step dad, for my aunts and uncles, for my cousins, for my friends, for myself.

I went through the next few months thinking that no one, not even my parents, got it. No one understood how I felt. I didn’t have anyone to talk to, but I didn’t really want to talk to anyone. I was convinced that no one in this world could possibly understand.

It probably sounds like I’m leading up to a moment when someone snapped their fingers and I woke up and realized that there were other people who understood or who, at least, cared enough to try, but that moment never came for me. It didn’t come in some big gesture, or a slap in the face, or a Heavenly voice, or even someone just saying, “Can I help?” It came in small moments. A smile from a friend when I had obviously been having a bad day, a blessedly quiet dinner, a random hug just because, an offer to talk whenever I needed it, a pat on the shoulder from a teacher who normally acted like they didn’t care. I never had that one, big, defining moment, but I didn’t need one. I didn’t want to share this grief with anyone. I needed it to just be mine.

Some people need to hear that someone else feels like they do, and some need to have their own grief, but I know that whichever path is chosen, it is horrible to walk it by alone. It feels like no one in this world could possibly understand what you’re going through. I’ve been there, I know it feels like that, and I think that people often make the mistake of thinking that there is always someone who gets it, but there isn’t always someone who understands. It takes time. Grief always takes time.

One thing that I can say helped me is getting the opportunities to do things like this. I speak, and have spoken, at multiple functions for the Children’s Hospital of Pittsburgh, and now I am getting to write this article. The one big thing that I have learned is that a person will not heal if they don’t find an outlet. It’s important to let the grief change you into someone who your loved one would be proud of.

I have always been quiet, but I used to be shy. I have always been the one who doesn’t mind sitting in the background. I’m the one people come to for advice. I’m the one people come to when they just need someone to listen to them. I never talk to talk. Maggie always wanted me to be more outspoken and passionate in speech rather than in silence. Maggie would be proud of what I have done with my grief. I have discovered, through this mess, that I love to talk in front of people, and I love to help people in any way that I can. I have discovered that I have a voice, and that I want it to be heard.

It’s hard to learn how to live without them. If there is one thing, one piece of advice that I can give you about this grief it is this: a family who grieves together, stays together. It seems impossible to watch the people you love go through the hardest time in their lives, but it’s worth it to get to other side together.
“A 360 degree outlook is imperative, every person in a household matters, a death will affect each one differently but the impact will be just as profound on a child as on an adult” –AG (Mother of four children, two of which died of the same genetic condition)

The death and prolonged illness of a sibling profoundly impacts children regardless of their age and stage of development. Each child is unique, with individual needs and responses that often reflect their family’s particular culture, spiritual background, and family system. Through case examples, this article will: (1) review how the death and prolonged illness of a sibling impacts children at various ages; (2) identify interventions that can be used with grieving siblings; and (3) describe the roles and responsibilities of pediatric providers in supporting grieving children and their families.
How the death of a sibling impacts children at various ages

Case 1: Jacklyn was a 9-year-old girl with a neurodegenerative disorder resulting in severe dystonia, dementia, and ultimately death. She spent the last three months of her life in the intensive care unit, intubated, deeply sedated, and in restraints to prevent her from extubating herself during dystonic episodes. Jacklyn had two younger brothers, Jeremy (6 years old) and Isaac (3 years old). Her parents brought her brothers to visit her on a regular basis. As her disease worsened, both child life and social work provided concrete explanations and anticipatory guidance directly to the boys as their parents requested. Jeremy was very aware of his sister’s disease progression, frequently talked about his sister “going to heaven,” and openly expressed his sadness and anger. Their parents would describe Isaac as “clueless” and “ignoring conversations,” but often shared tales of his changed and erratic behavior. This included increased tantrums, frequent interruptions in sleep, regressed toileting habits, and decreased appetite. Child life and social work provided psychoeducation about age-appropriate reactions and strategies for meeting both brothers’ needs given their ages and levels of processing.

All children respond to serious life changes even though they may express it differently. From a very young age, children are attuned to stressors in their environment, routine, and social supports. They respond to the emotional reactions of those they love and are curious about better understanding the people and the world around them.

Children who experience the illness and death of a sibling are no different and often have to make sense of tragedy and major family adjustments in the context of ongoing development. This leaves children particularly vulnerable, but also open to supports that reflect their specific needs. From early infancy, a child can be comforted by his or her parents and loved ones. The sense of security felt through the attention to basic needs (feeding, bathing) and comfort (such as sucking, swaddling, shushing) make infants feel safe and protected. For toddlers, meeting these basic needs and the additional needs of consistent parenting and social-emotional support is critical. For those in early childhood, routines and social-emotional support become paramount. These children often look to a wider range of caregivers for support and understanding about things happening around them. For older school-age children, peers and relationships with other adults become important. For adolescents, peers may be the main source of support that serves as a holding environment for processing emotions and grief. Children of all ages look to others for cues about how to process emotional information and how to react. Table 1 outlines typical stages in child development with key concepts about how children understand death and loss and how their grief may manifest depending on their particular age and developmental stage.

<p>| Table 1: Ages and Developmental Understanding of Death |
|-----------------|-----------------|-----------------|-----------------|
| Age Group       | Conceptualization | Interventions                      | Example of age-appropriate language |
| 0-2 years       | • No cognitive understanding of death | • Maintain routines | “Suzy did not want to leave.” |
|                 | • Concern for experience of death as abandonment and/or separation | • Avoid separation from significant others | |
|                 | • Understand events in terms of direct experience | • Presence is more important than words | |
|                 | • Identify when adults are in distress | | |</p>
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<tr>
<th>Age Group</th>
<th>Key Points</th>
<th>Sample Statement</th>
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| 2-6 years  | • Believe death is temporary and reversible  
• Often blame themselves for the death  
• Much curiosity  
• Magical thinking                | “Bobby is dead, that means he won't ever live with us again, but we will always remember him.” |
| 6-8 years  | • Death is final and irreversible  
• Fear death  
• Concerned for other’s safety  
• Believe death is not universal | “When someone dies, that means their body is no longer working. Their heart stops beating, they no longer need to eat or sleep, their brain stops thinking, and they no longer feel any pain. They don’t need their body any longer. That means we will never see them again as we could before.” |
| 8-12 years | • Understand death is final, irreversible, and universal  
• Comprehend biological aspects of death  
• Morbid curiosity  
• Intellectualize death        | “I, too, am very sad that Katie is sick. Grandma is going to come take care of you while I go to the hospital with Katie, but we will have Grandma bring you to the hospital if something happens.” |
| 12-18 years | • Adult understanding that death is inevitable  
• Ability to think abstractly and philosophically  
• Curiosity surrounding existential implications of death | • Support independence and access to peers  
• Monitor social media  
• Maintain familiar routines | “If you want to talk, I am here to listen. If you do not want to, then I am here if/when you do. I can’t imagine what you are feeling right now, and I want you know I am here to support you.” |

Interventions that can help grieving siblings

Case 2: Alexandra was a 2-year-old girl with relapsed metastatic cancer. After spending 8 months in and out of the hospital receiving treatment, the medical team shared their concerns that her cancer was no longer responding to treatment, and given the rapid progression of her tumor, she likely had days to short weeks to live. Alexandra had a 4-year-old brother named Andrew who referred to his sister as his best friend. Their parents explained how Andrew was very protective of his sister and loved her deeply. They also shared that Andrew had been extremely lonely when she had been in the hospital and frequently asked questions about when his sister would be better and able to be at home all the time. Their parents asked for assistance in communicating with him about Alexandra’s disease progression. Andrew liked art and specifically enjoyed drawing. Through the use of crayons, Andrew was able to draw pictures of his sister’s “bad balls in her tummy” and expressed the desire for “the doctors to take bad balls out of her tummy so she can come home.” Using Andrew’s language and frame of reference, the social worker asked Andrew about the circumstance in which the doctors were unable to remove “balls from her tummy,” and he was able to articulate that he would “be very sad, because then my sister won’t feel better.” As an active 4-year-old boy, providing Andrew with an activity to aide in communication and focus proved helpful in deciphering his understanding and concerns. This care required careful collaboration between their parents, social work, child life, and a child psychologist.

Despite the natural changes in development, children who are grieving the illness and death of their sibling need additional support to process what is happening to their brother or sister and within their family. Interventions that help children are often tailored to the particular needs of the individual child and are sensitive to a family’s cultural, spiritual, and social norms. Exploring these aspects of a family system are important first steps. Questions about previous experiences with death (such as the loss of a grandparent or pet), faith traditions, and how information is shared within the family can be helpful.

Further exploring the psychological well-being of the family is also important (parents with history of anxiety or depression, how the child has coped in the past with challenges). Providers can assist by helping parents to identify additional caregivers who may be available (grandparents, close family friends) to provide consistency, attentiveness, and varying types of support to the child. These caregivers may be able to play a crucial role in maintaining routines and normal activities. Individualized family considerations and structural supports can yield helpful suggestions and clinical recommendations to those aiding children and families during their loss and grieving process.

In addition to exploring these specific family aspects, there are also more generalizable ways in which to support children and their families. Families often desire maintaining a sense of hopefulness and maximizing relationships between siblings when struggling with the illness of a child. Attending to and promoting these aspects of care often involve supporting the child in memory-making activities that can help children process and cope with grief after their sibling’s death. Memory-making activities can include handprints/footprints, molds, decorating their sibling’s room, generating music, writing songs or plays, creating artwork, video/photography, and writing letters/journaling. The individual interests of a child and/or the specific interests that the child and his or her sibling share (playing videogames, a specific activity, or sport) can guide which activities will be most meaningful. Helping with care needs (household chores, physical care of their sibling) can also involve siblings in purposeful ways as long as these
activities are based on the specific child’s comfort and interest. Box 1 lists some suggested techniques to employ with grieving siblings.

Communication is another critical aspect in supporting siblings. Communication that is clear, honest, age-appropriate, and sensitive to family values is essential for children experiencing the loss of their sibling. In fact, bereaved siblings have specifically articulated the necessity of communication that meets their individual needs as an incredibly important part of supporting them through loss.\textsuperscript{5} Time taken to clarify what specific questions the child has and how he or she wants information shared with them can be very important in making sure a child’s communication needs and preferences are being fully addressed. Each child is different in how much information they wish to know, what types of things they are worried about/have questions about, and how they want to receive information. When appropriate, it is best to explore this directly with each individual child and family. Often repetition of developmentally-appropriate information is needed to reassure and/or explain what is happening when a child is experiencing grief or illness of his or her sibling.

Allowing children autonomy and a sense of control whenever possible can also be extremely helpful and empowering. Children may want to decide how and when to be with their sibling who is ill, determine what memory making activities they participate in and how information is shared.\textsuperscript{4,5} Allowing children to guide these aspects of care respects their personal needs and sense of autonomy. Children may also need breaks from time with family and dedicated time to participate in regular activities (going to school, participation in activities, bonding with peers, alone time). Following the death of a sibling, children may benefit from ongoing choice around attending funerals, talking about their sibling, and creating their connection experiences. These are typical aspects of the grieving process and should be expected when meeting each individual child’s needs.

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<tr>
<th>Box 1: Strategies for Engaging with Siblings/Pediatric Relatives</th>
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<td>• Getting on their level-physically/developmentally</td>
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<td>• Just showing up</td>
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<tr>
<td>– Becoming a familiar face over time</td>
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<td>• Allowing interactions to be on their terms</td>
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<td>– Incremental steps</td>
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<td>• Creativity in language</td>
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<td>– Art, music, stories</td>
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<tr>
<td>• Using safe objects and safe people</td>
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<td>– Talking to a toy</td>
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<td>– Talking about friends</td>
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The roles and responsibilities of pediatric providers in supporting grieving children and their families

Case 3: Kathryn was a 3-year-old girl with complex congenital heart disease who spent the majority of her life in the hospital. Her family lived over two hours away from the hospital, so during admissions, her mother stayed with her. Her 13-year-old sister, Amanda, continued her normal routine at home with her father. Amanda was able to visit Kathryn during weekends, but because of scheduling differences, the palliative care team did not meet Amanda until the day that Kathryn died. Her death was sudden, as she experienced a cardiac arrest following a period of relative stability. Kathryn died acutely just days prior to a planned discharge home. Kathryn’s mother was in a state of shock as she cradled her daughter’s body. Staff members contacted her father to notify him and he arrived soon after with Amanda. While the palliative care team had never met Amanda in person, they had had many conversations with her mother about her personality, involvement, and understanding of Kathryn’s condition. Their parents were very focused on Kathryn that day, consumed by their own grief, and were therefore unable to provide their older daughter with the support and attention that she needed. The palliative care team and various other staff members were able to provide attention, support and honest age-appropriate information about her sister’s death. Amanda later shared her gratitude for this attention as she knew that her parents had to be with her sister and was so glad she was not alone. This interaction also established rapport for continued bereavement support for their parents as well as for Amanda.
Children experiencing the loss of a sibling may have new or changing behavioral problems associated with the stress, social, emotional, and physical aspects of their changing family. A child may become more withdrawn or may “act out” in ways a family has not previously experienced. Parental coping and consistent caregiver support can influence these reactions. Families may benefit from clinicians who are able to provide expertise and support, as well as flexibility in meeting individual needs.

Thankfully, there are many providers who can help children and families during this process. Box 2 lists some of the specialists trained to address different aspects of preparing for the loss and grief associated with the prolonged illness and death of a sibling. Some of these specialists work more directly with parents/families, while others are dedicated to the child. Role modeling may occur in these relationships, as parents learn more about comforting their grieving child through watching the work of specialists who have training and experience. Although the type of support may not “directly” address the active grieving process, finding ways of supporting siblings in doing what they feel is important and expressing their own emotional reactions can be immensely therapeutic. Often, it is the consistent presence of providers and lasting connections, rather than the specific interventions or advice/words being spoken that are the most helpful to children. Being open to relationships that develop and providers sharing in the care of these children and their families is often necessary as the needs of even one family can be overwhelming for a single provider.

Recognizing these relationships and working with professionals who can be flexible in their role and also support one another can lead to sustainable practices for supporting and educating families during these life-changing moments.

**Conclusion**

Attending the needs of siblings who are grieving during the illness trajectory, as well as to bereaved siblings after the loss of a child, are critical aspects in providing true family-centered care. These losses stay with children throughout their lifetime. There is so much that can be done to foster a sense of hope and meaning during this process that can later impact a child’s grief. Fortunately, there are many trained professionals who can share in this important work.

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<th>Box 2: Providers Who Can Support Grieving Siblings and Their Families</th>
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References


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WHAT SIBLINGS WOULD LIKE PARENTS AND SERVICE PROVIDERS TO KNOW

Don Meyer
Director, Sibling Support Project
A Kindering Center Program
Seattle, WA
donmeyer@siblingsupport.org
www.siblingsupport.org

In the United States, there are over 4.5 million people who have special health, developmental, and mental health concerns. Most of these people have typically developing brothers and sisters. Brothers and sisters are too important to ignore, if for only these reasons:

- These brothers and sisters will be in the lives of family members with special needs longer than anyone. Brothers and sisters will be there after parents are gone and special education services are a distant memory. If they are provided with support and information, they can help their sibs live dignified lives from childhood to their senior years.

- Throughout their lives, brothers and sisters share many of the concerns that parents of children with special needs experience, including isolation, a need for information, guilt, concerns about the future, and caregiving demands. Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressure to achieve.

Despite the important and life-long roles they will play in the lives of their siblings who have special needs, even the most family-friendly agencies often overlook brothers and sisters. Brothers and sisters, often left in the literal and figurative waiting rooms of service delivery systems, deserve better. True “family-centered” care and services will arrive when siblings are actively included in agencies’ functional definition of “family.”

The Sibling Support Project facilitated a discussion on SibNet, its online group for adult siblings of people with disabilities, regarding the considerations that siblings want from parents, other family members, and service providers. Below is a discussion of themes discussed by SibNet members and recommendations from the Sibling Support Project:

1. Siblings Have a Right to Their Own Lives. Throughout their lives, brothers and sisters may play many different roles in the lives of their siblings who have special needs. Regardless of the contributions they may make, the basic right of siblings to their own lives must always be remembered. Parents and service providers should not make assumptions about responsibilities that typically developing siblings may assume without a frank and open discussion. “Nothing about us without us”— a phrase popular with self-advocates who have disabilities — applies to siblings as well. Self-determination, after all, is for everyone — including brothers and sisters.

2. Siblings Have a Right to Have Their Concerns Acknowledged. Like parents, brothers and sisters will experience a wide array of often-ambivalent emotions regarding the impact of their siblings’ special needs. These feelings should be both expected and acknowledged by parents and other family members and service providers. Because most siblings will have the longest-lasting relationship with the family member who has a disability, these concerns will change over time. Parents and providers would be wise to learn more about siblings’ life-long and ever-changing concerns.

3. Typically Developing Siblings Deserve Realistic Expectations. Families need to set high expectations for all their children. However, some typically developing brothers and sisters react to their siblings’ disability by setting unrealistically high expectations for themselves — and some feel they must somehow compensate for their siblings’ special needs. Parents can help their typically developing children by conveying clear expectations and unconditional support.
4. **Typically Developing Siblings Have a Right to Typical Behavior.** Although difficult for parents to watch, teasing, name-calling, arguing and other forms of conflict are common among most brothers and sisters — even when one has special needs. While parents may be appalled at siblings' harshness toward one another, much of this conflict can be a beneficial part of normal social development. A child with Down syndrome who grows up with siblings with whom he sometimes fights will likely be better prepared to face life in the community as an adult than a child with Down syndrome who grows up as an only child. Regardless of how adaptive or developmentally appropriate it might be, typical sibling conflict is more likely to result in feelings of guilt when one sibling has special health or developmental needs. When conflict arises, the message sent to many brothers and sisters is, “Leave your sibling alone. You are bigger, you are stronger, you should know better. It is your job to compromise.” Typically developing siblings deserve a life where they, like other children, sometimes misbehave, get angry, and fight with their siblings.

5. **The Family Member with Special Needs Also Deserves Realistic Expectations.** When families have high expectations for their children who have special needs, everyone will benefit. As adults, typically-developing brothers and sisters will likely play important roles in the lives of their siblings who have disabilities. Parents can help siblings now by helping their children who have special needs acquire skills that will allow them to be as independent as possible as adults. To the extent possible, parents should have the same expectations for the child with special needs regarding chores and personal responsibility as they do for their typically developing children. Not only will similar expectations foster independence, it will also minimize the resentment expressed by siblings when there are two sets of rules — one for them, and another for their sibs who have special needs.

6. **Siblings Deserve The Right to a Safe Environment.** Some siblings live with brothers and sisters who have challenging behaviors. Other siblings assume responsibilities for themselves and their siblings that go beyond their age level and place all parties in vulnerable situations. Siblings deserve to have their own personal safety given as much importance as the family member who has special needs.

7. **Siblings Deserve Opportunities to Meet Peers.** For most parents, the thought of “going it alone,” raising a child with special needs without the benefit of knowing another parent in a similar situation would be unthinkable. Yet, this routinely happens to brothers and sisters. Sibshops, online groups such as SibNet and SibTeen, and similar efforts offer siblings the common-sense support and validation that parents get from Parent-to-Parent programs and similar programs. Brothers and sisters — like parents — like to know that they are not alone with their unique joys and concerns.

8. **Siblings Deserve Opportunities to Obtain Information.** Throughout their lives, brothers and sisters have an ever-changing need for information about their sibling’s disability, and its treatment and implications. Parents and service providers have an obligation to proactively provide siblings with helpful information. Any agency that represents a specific disability or illness and prepares materials for parents and other adults should prepare materials for siblings and young readers as well.

9. **Siblings Should Be Included in Addressing Concerns about the Future.** Early in life, many brothers and sisters worry about what obligations they will have toward their sibling in the days to come. Ways parents can reassure their typically-developing children are to make plans for the future of their children with special needs, involve and listen to their typically-developing children as they make these plans, consider backup plans, and know that siblings’ attitude toward the extent of their involvement as adults may change over time. When brothers and sisters are “brought into the loop” and given the message early that they have their parents’ blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation. For their own good and for the good of their siblings who have disabilities, brothers and sisters should be afforded the right to their own lives. This includes having a say in whether and how they will be involved in the lives of their siblings who have disabilities as adults, and the level, type, and duration of involvement.
10. **Family Discussions with Siblings Should Include Both Sons and Daughters.** Just as daughters are usually the family members who care for aging parents, adult sisters are usually the family members who look after the family member with special needs when parents no longer can. Serious exploration of sharing responsibilities among siblings — including brothers — should be considered.

11. **Communication Among Family Members Should Include All Children.** While good communication between parents and children is always important, it is especially important in families where there is a child who has special needs. An evening course in active listening can help improve communication among all family members, and books, such as *How to Talk So Kids Will Listen and Listen So Kids Will Talk and Siblings Without Rivalry* (both by Adele Faber and Elaine Mazlich) provide helpful tips on communicating with children.

12. **Siblings Deserve One-on-One Time with Parents.** Children need to know from their parents' deeds and words that their parents care about them as individuals. When parents carve time out of a busy schedule to grab a bite at a local burger joint or window shop at the mall with their typically developing children, it conveys a message that parents “are there” for them as well and provides an excellent opportunity to talk about a wide range of topics.

13. **Every Child’s Achievements and Milestones Should Be Celebrated.** Over the years, we’ve met siblings whose parents did not attend their high school graduation — even when their children were valedictorians — because the parents were unable to leave their child with special needs. We’ve also met siblings whose wedding plans were dictated by the needs of their sibling who had a disability. One child’s special needs should not overshadow another’s achievements and milestones. Families who seek respite resources, strive for flexibility, and seek creative solutions can help assure that the accomplishments of all family members are celebrated.

14. **Siblings Will Be Influenced More By Their Parents’ Perspectives Than by the Actual Disability.** Parents would be wise to remember that the parents' interpretation of their child's disability will be a greater influence on the adaptation of their typically developing sibling than the actual disability itself. When parents seek support, information, and respite for themselves, they model resilience and healthy attitudes and behaviors for their typically developing children.

15. **Siblings Should Be Included in the Definition of “Family.”** Many educational, health care, and social service agencies profess a desire to offer family-centered services but continue to overlook the family members who will have the longest-lasting relationship with the person who has the special needs — the sisters and brothers. When brothers and sisters receive the considerations and services they deserve, agencies can claim to offer “family-centered” — instead of “parent-centered” — services.

16. **Parents and Care Providers Should Actively Reach Out to Brothers and Sisters.** Parents and agency personnel should consider inviting (but not requiring) brothers and sisters to attend informational, IEP, IFSP, and transition planning meetings, and clinic visits. Siblings frequently have legitimate questions that can be answered by service providers. Brothers and sisters also have informed opinions and perspectives and can make positive contributions to the child’s team.

17. **Parents and Care Providers Should Make Efforts to Learn More About Life as a Sibling.** Anyone interested in families ought to be interested in siblings and their concerns. Parents and providers can learn more about “life as a sib” by facilitating a Sibshop, hosting a sibling panel, or reading books by and about brothers and sisters. Guidelines for conducting a sibling panel are available from the Sibling Support Project and in the Sibshop curriculum. Visit the Sibling Support Project’s website for a bibliography of sibling-related books.

18. **Communities Should Create Local Programs Specifically for Brothers and Sisters.** If your community has a Parent-to-Parent Program or similar parent support effort, a fair question to ask is: why isn’t there a similar effort for the brothers and sisters? Like their parents, brothers and sisters benefit from talking with others who “get it.” Sibshops and other programs for preschool, school age, teen, and adult
siblings are growing in number. The Sibling Support Project, which maintains a database of over 450 Sibshops and other sibling programs, provides training and technical assistance on how to create local programs for siblings.

19. **Brothers and Sisters Should Be Included on Advisory Boards and in Developing Policies Regarding Families.** Reserving board seats for siblings will give the board a unique, important perspective and reflect the agency's concern for the wellbeing of brothers and sisters. Developing policies based on the important roles played by brothers and sisters will help assure that their concerns and contributions are a part of the agency's commitment to families.

20. **Communities Should Fund Services for Brothers and Sisters.** No classmate in an inclusive classroom will have a greater impact on the social development of a child with a disability than brothers and sisters will. They will be their siblings' life-long "typically developing role models." As noted earlier, brothers and sisters will likely be in the lives of their siblings longer than anyone — longer than their parents and certainly longer than any service provider. For most brothers and sisters, their future and the future of their siblings with special needs are inexorably entwined. Despite this, there is little funding to support projects that will help brothers and sisters get the information, skills and support they will need throughout their lives. Governmental agencies would be wise to invest in the family members who will take a personal interest in the wellbeing of people with disabilities and advocate for them when their parents no longer can. As one sister wrote: "We will become caregivers for our siblings when our parents no longer can. Anyone interested in the welfare of people with disabilities ought to be interested in us."

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About the Sibling Support Project

The Sibling Support Project, believing that disabilities, illness, and mental health issues affect the lives of all family members, seeks to increase the peer support and information opportunities for brothers and sisters of people with special needs — and to increase parents’ and providers’ understanding of sibling issues.

Our mission is accomplished by training local service providers on how to create Sibshops (lively community-based for school-age brothers and sisters); hosting workshops, online groups, and websites for young and adult siblings; and increasing parents’ and providers’ awareness of siblings’ unique, life-long, and ever-changing concerns through workshops, websites, and written materials.

Based in Seattle since 1990, the Sibling Support Project is a national effort dedicated to the interests of over six million brothers and sisters of people with special health, mental health and developmental needs.

For more information about Sibshops, sibling issues, and our workshops, online groups and publications, contact:
Don Meyer
Sibling Support Project
A Kindering Center program
6512 23rd Ave NW #322
Seattle, WA 98117
206-297-6368
donmeyer@siblingsupport.org
www.siblingsupport.org

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We live in a small community. It is one of those places where all the kids are introduced at birth, then attend the same church, daycare, and schools all the way to graduation. Because of this, when tragedy hits, it hits home hard. I remember the night I heard of the tragic accident of a 16-year-old boy died from an accidental gunshot wound. This accident occurred at house party where two young boys decided to play with, what they thought, was an unloaded handgun; and one friend accidently shot his best friend. To make a terrible situation worse, the entire party witnessed the shooting, including the victim’s younger sister. I saw this on the news and immediately felt sadness for the teens, their parents, and the community. Little did I know I was about to enter their world and join them in this grief journey.

Several weeks after the accident, my hospice was contacted by the parents of the children who had witnessed the shooting, seeking a “teen grief support group.” I spoke with all of the parents and we determined that the best approach would be to hold a closed group solely for the teens involved. I had been working as the Children’s Support Specialist for about five years and felt prepared to tackle this group. I gathered background on this group of friends, brushed up on my group skills, and pre-planned a general list of topics for a 6-8 week group.

The first night of the group I arrived ready to listen, support, and help this group heal. I expected normal chatty teens, but what I got was eight teens with arms crossed, scowling, and it was obvious they were not willing participants of this group. To their credit, they were all very respectful in their silence, but they let it be known they were definitely not there by choice. It turned into the longest hour of my career. I quickly realized that what I had “planned” was not going to work and I needed rethink my approach.

I left that night feeling inadequate and that I had let these kids down when they needed someone the most. In the past, I planned my groups out and knew what I was going to say and do to elicit conversation and reflection… it had always worked! This time I was at a loss of how to reach them. I considered seeking another counselor to help them. Maybe someone one “more skilled” could do a better job. Luckily, I had amazing mentors that I could seek out for wisdom and insight on what I was doing wrong. Sometimes knowing we are not alone in the field, and knowing when to seek help, is the best tool in our tool box.

After getting guidance from my mentors, I regained my confidence and returned for round two with the teens. This time they were somewhat more talkative but not willing to "go there." I shared with them that because of this shared loss they are now part of a club that no one asked to be a member of and no one asks to join. I explained that they were not going to be forced or expected to share with the group, but I hoped they would. During this session I provided each member with a small journal and discussed the power of "just getting it out" and then I defined what "it" was. "It" is pain, grief, guilt, anger, confusion, anxiety, and sometimes even laughter. I discussed how someone might struggle with each of these emotions and no feeling is wrong. I got a few head nods, a few verbal agreements, and a few silent stares. As expected, no one eagerly started writing, so I posed a simple challenge. The challenge was this: during each session they were not required to talk if they didn’t want to; however, they had to at least respond in their journal. They could write sentences, one word, or even draw a picture. All agreed to this challenge. For that night’s homework I asked them to finish this statement, "If only you knew.....” That was all there was to it, just finish the statement.

Upon my return to the next session, I asked if anyone wanted to share and one person did. She shared “If only you knew how hard it is to be alone with my thoughts.” We discussed this as a group and several
members shared that they also felt this way. She shared that she also felt tremendous guilt for “not knowing the gun was loaded” and for “allowing him to play with a gun; Dad taught us better than that!” Again, more head nods and more connections were made.

Each session ended with a new statement for them to finish, with no pressure to share. The statements were “If only…”, “I miss…”, “Now I’m…”, “I can only hope…”, and “I learned….” On the next to last session, I asked if they felt comfortable sharing their writing with me. Surprisingly, they all agreed. Some chose to share during group time, and this opened up great conversations which allowed them to see that they were all struggling with similar feelings and emotions, but each in their own way. We had several “me, too” and “I never knew you felt that way, too” statements that night. A few others chose to turn in their journal for me to review in private.

To my surprise, each page was full. Each page was heavy with grief, pain, guilt, and anger. But, just as I had hoped, as I turned each page their expressions transitioned from a place of hopelessness to hope. None of these teens were “healed,” but the once-fresh wounds were beginning to turn into scars. I had used the analogy in one session that our grief never heals, it’s a scar we carry. Scars show that you have lived through something painful, but you are able to move forward. I reminded them that memories will still make them sad and sometimes make them laugh, and both are ok. What I noticed in reading these journals, was the strong similarities in all of the writing. They were expressing the same emotions, all in their own personal way, but overall, the same. Because of this, I took all of their writings and journal entries and complied it into a poem, “If Only,” as a way to applaud their courage to share, their participation in group, and finally, to show them how connected they were in their grief.

I believe they were able to find some peace in their grief, and I hope they are still supporting one another in this “club” to this day. They will never know how much they taught me in one group, compared to what I ever read in textbooks or from attending conferences. We can have the best intentions and think we know best, but our clients need to be the ones to tell us what they need.

If Only…
I could have been there
I could have saved you
I could have stopped it
I didn’t feel so alone
I could cry
I could talk to someone and tell them how much I hurt
I had one more day…one more hour…one more second

I Miss…
Your texts
Your friendship
Your hugs
Your face
Your life

If Only you knew…
How hard it is for you to be gone
How it feels to lose the one you love
How hard it is to smile when all I want to do is hide
How hard I try to lock it up inside
How hard it is to be alone with my thoughts…with my sadness
How hard it is to sleep with all these regrets raging in my head

Now I’m…
Sad
Angry
Sorry
Cautious
Tired
Guilty
Alone

I can only Hope to find…
Peace
Trust
Laughter
Forgiveness
Strength

I learned…
I do not have to hang on to His death to remember His life
"CAN YOU PLAY WITH ME?"
USING PLAY TO SUPPORT THE SIBLINGS OF PEDIATRIC HOSPICE PATIENTS

Lenze Ramage, CCLS
Certified Child Life Specialist
Hands of Hope Pediatric Comfort and Palliative Care
Greenville, SC
Lenze.ramage@handsofhopesc.net

Stephanie Lamy Mishoe, MEd, CCLS
Certified Child Life Specialist
Hands of Hope Pediatric Comfort and Palliative Care
Summerville, SC
Stephanie.mishoe@handsofhopesc.net

For a child at any age, having a seriously-ill or dying sibling is very difficult to cope with and understand. Such children often experience intense new emotions while observing a myriad of reactions from their parents and other trusted family members. These siblings are trying to process the why, the how, the “will it happen to me?” and many other questions. Children can have a difficult time verbalizing feelings and fears. Oftentimes, these children have never felt these strong emotions before, are unsure of how they are supposed to react, or are afraid how others around them will react. During the natural art of play, many of these themes emerge. Play allows these children to process their world in a safe way so that they can understand and express themselves freely.

While supporting a boy whose baby brother had died, we were playing with arts and crafts. I presented him with a blank shape of a person. He asked what he was supposed to do with it, but I gave no direction. I simply replied, “You can do what you want.” He chose for it to be his little brother who had died. He said, “I think this is what the baby would look like when he got big.” This statement allowed me to expand his play with facilitative responses geared to continue this theme. He was hesitant to engage in this at first, but then jumped at the chance to play about his little brother. He first pretended that his paper brother was in heaven, then pretended that he was playing sports. He was able to imagine a whole life for him. It was therapeutic for him to think and play through these questions he had about the death. He was also able to play through what it would have been like if his brother was still alive.

Play gives children an outlet for self-expression. According to Dr. Garry Landreth of the Center for Play Therapy, “Toys are used like words for children, and play is their language.” Children are often better able to express themselves through their manipulation of toys than through their use of words. Play can reveal the child’s experience, their reactions to and feelings about what was experienced, what the child wants, wishes and needs as well as the child’s self-perception. During play the child experiences a supportive environment to express many emotions such as anger, sadness, or fear. Children are able to play through an experience while staying a safe distance from the reality. Even if the play seems unrelated to the event, it is still helping them process their own experience. You will often see themes (especially in younger children) of aggression, loss, and confusion about death through play, such as hiding and uncovering toys, crashing cars, and destroying and building.

Play is also a way for the siblings to build memories together. When children are seriously ill, sometimes their siblings become afraid to play with them and even avoid them altogether. Encouraging the children to spend time together just being silly or engaging in free play without the worries of medicine, hospitals, or death can bring so much joy and can build memories that will last long after the patient has died. Facilitating this play can also address fears siblings may have about what could happen, and encourages them to play with their sibling more often. If the ill child has experienced a decline (such as losing the ability to talk or becoming bedbound), their siblings may be unsure of how to adapt the play experience. By helping to facilitate the play and giving ideas of things they can still do together, an experienced child life specialist can assuage these fears and assist in keeping the sibling bond intact.
Children of all ages want independence and control in their lives. This is often why siblings of ill children begin to act out—because they are losing any of the control and normalcy that they had in their lives. They are unable to make sense of the changes occurring around them. With a sibling who is dying, there is so much that is beyond their control. They cannot control that their sibling will die. They cannot control the doctors’ appointments, the people visiting the house, their parents’ reactions, or even their own feelings; however, through their play, children can experience the feeling of being in control even when they are not in control of the reality. This sense of being in control during play is essential for positive coping.

Play is always vital in the lives of children, but especially so during or after a traumatic event such as the death of a sibling. Through play they are able to live out their past experience and their feelings about this experience. Allowing a grieving child to play freely and without restrictions will support their natural self-healing and development of crucial coping strategies.
DIPG (Diffuse intrinsic pontine glioma) is a non-curable brain tumor that begins growing in the brain stem (DIPG Registry, 2014; St. Jude Children’s Research Hospital, 2017). The Michael Mosier Defeat DIPG Foundation (2017) notes DIPG is more common among children ages five to ten, with approximately 200-400 children diagnosed each year in the United States, and the median survival rate is nine months after diagnosis. When we think about this population and those who are now facing the heartbreaking fact that they are going to lose a child they love, it is natural for us as providers to want to support the parents, siblings, and any additional family involved to the best of our abilities. But what about their friends?

We know children begin seeking out support from friends and peers as they enter the school years, and friendships become ever increasingly important part of their development into adolescence (Rollins, Bolig, & Mahan, 2005). Dyregrov (2008) notes the significant lack of research regarding the effects the death of a friend can have on a child, and has found the death of a friend can not only lead to strong grief reactions among the child’s peers inside and outside of the classroom, but approximately 20% of these children will continue to exhibit these strong grief reactions up to nine months after the death (Dyregrov, Bie Wikander, & Vigerust, 1999). I knew from my educational background that “anyone old enough to love, is old enough to grieve.” I knew the friends of a child were impacted by the child’s death, and I knew there were many therapeutic interventions we could provide to support the people loved by the children we served. What I didn’t know was the impact we could make in the school setting, and how many lives we could touch until I met Morgan.

I walked in the door of a beautiful home with the hand-written notes I had taken while reading the reports sent to us from St. Jude Children’s Research Hospital. “Hi Morgan! My name is Magellan and I’m a child life specialist.” She giggled with glee; clearly, she was familiar with our services. I quickly learned Morgan was full of life. She loved to laugh, draw with sidewalk chalk, paint, sing, play with her friends, and she absolutely adored her three-year-old little brother. Morgan also loved school. The family was clear in their desire for child life involvement, which included assisting Morgan in her ability to cope with the changes she would continue to experience due to her brain tumor, supporting her younger brother, and providing opportunities for memory-making and legacy work. We agreed to start with weekly visits because Morgan had a slow-to-warm temperament and would need time to build a trusting rapport with me.

The next week, I went to visit Morgan on MLK Day. I only remember this because she wanted to go on a walk to her elementary school up the street, and she got very upset when we got there and found they were closed. Morgan’s dad pushed her wheelchair up to the door so she could look inside, and she let us know she was missing her classmates and friends. I remember asking her dad what he thought about Morgan going to school again on her good days. He was very hesitant, and honestly, I was too. How would the children react? What questions would they have? How do we explain her illness and prognosis to them? What if they are mean? What would the parents say? All of these questions raced through our minds, but one thing I was certain of: Morgan missed her friends and we needed to do something about that.

A week later, Morgan’s parents and I met to discuss what the goals were for Morgan going back to school. My primary goal as a child life specialist was to make sure this was in Morgan’s best interest, a positive school re-entry experience, and to be an additional layer of support for the school staff. We talked about what Morgan returning to school could look like, and they agreed to me speaking with the principal and school counselor later that afternoon. Morgan’s parents trusted us to meet without them, as they worked in the afternoon while Morgan napped. They trusted us to work together to make this the best
experience for everyone involved, and we didn’t want to mess this up. We couldn’t mess this up.
Morgan’s teachers were able to step away from their classrooms to be a part of this meeting, as well as
the school nurse. The staff was already aware of Morgan’s diagnosis and prognosis, and the staff was
aware the children, at minimum, knew she was “sick”. We spent the entire afternoon addressing every
issue we could come up with that could occur. We examined class schedules, personalities of the
children, and what specific portions each person would be responsible for throughout this process.

The week before spring break included educational sessions for both the parents and staff. The parent
presentations were focused on what to tell a child when a classmate/friend has a terminal diagnosis. We
educated on the importance of being open and honest with children, and utilizing simple, truthful,
developmentally appropriate explanations. We encouraged them to use the words “cancer” or “brain
tumor,” to let them know you can’t catch cancer, and no one did anything to cause Morgan’s cancer. We
explained the physical changes Morgan had experienced since she had left school, including being
wheelchair bound, ankle braces, slurred speech, and weight gain due to steroids. She also developed an
increase in the outward expression of her emotions, including increased crying and moaning when
something was wrong (i.e., pain, tired, thirsty, hungry, uncomfortable in her chair). We talked about the
importance of preparing the children for what they would see, so they could ask questions before seeing
Morgan.

We were also able to provide education on anticipatory grief, and ways to support children not only
anticipating the death of a friend, but how to support their children in the aftermath as well. We duplicated
this training for the staff, but modified it for the classroom setting. I was asked to help the school
counselor meet with Morgan’s classmates to provide education on cancer, help them to understand the
changes they would see in Morgan, and help prepare them for her visit. I agreed, and the principal sent
consent forms and photography releases home with the children later that week. We were specific on
what would be discussed with the children, and what Morgan’s visit would consist of, as transparency with
parents is critical in these moments. We didn’t want anyone to be caught off-guard or unaware of what
their children would be learning at school in the next few weeks. Out of 50 children, not one parent
declined their child’s involvement.

After spring break, I facilitated the classroom interventions alongside the school counselor and teachers.
We read a book to explain cancer, then discussed Morgan’s changes as a group. We wanted the children
to focus on things that would be the same about Morgan, rather than different, and I will never forget
hearing the children’s answers, including “her smile,” “her heart/love,” and “her hair bows.” The children
worked on a welcome back poster for Morgan, and were so excited to see their friend. It was finally time
for Morgan’s visit, and I don’t think I’ve ever been that nervous. I was so grateful one of our pediatric
nurses came with me for moral support, and to take photos for the family. Morgan and her parents came
through the door of the school and were welcomed with open arms. We met in the library and one of the
teachers read “The Giving Tree.” We talked about how we give to others, and how they would be
decorating a thumbprint tree to give Morgan’s family. The other teacher facilitated the activity with the
children, and they had set-up stations for the children to rotate through so Morgan would not be
overwhelmed by the number of kids at the thumbprint station with her. You could physically see the
impact we were making in this moment. Morgan, her parents, and the staff were so grateful for this
opportunity, and tears of joy and love were shed throughout the morning. Morgan beamed with
happiness, and her contagious smile never once disappeared.

After this visit, we transitioned hands-on support to the school counselor. She had always had the right
tools in her toolbox to support the kids due to her previous work experiences, and I knew she would do a
phenomenal job. This experience ended up being the breakthrough I needed with Morgan. From that
moment on, she trusted me. She engaged more in our visits, and opened up more about her needs.

Unfortunately, we were not able to facilitate another school visit for Morgan due to her disease
progression. About six weeks later, we realized there was a high change: Morgan wasn’t going to make it
to her 7th birthday the following month. The family decided to celebrate her birthday early, and we
coordinated with the school counselor to have her closest group of friends from school walk over for an
ice cream sundae party. If we couldn’t take Morgan to school, why not bring her friends to her? The six little girls who came over spent the next hour talking and laughing with Morgan. Looking back, I firmly believe deep down these children knew what was going on. We weren’t hiding anything from them, but we wanted to leave that conversation to their parents and we knew those conversations would be coming soon if they hadn’t happened prior to this visit.

Two weeks later, the principal had to send the heartbreaking email notifying parents Morgan had died. The school was prepared to talk with the kids, and the school counselor, principal, and nurse were prepared to support the children and staff. The staff had regular debriefings and multiple staff members kept an open door policy for the children who needed additional one-on-one support while at school. They also dedicated a bench in Morgan’s honor before school let out for the summer.

I look back and question if any of this would have happened had Morgan not let us know she needed her friends, and in turn, they needed us. Unfortunately, stories like this are not always the case when it comes to classmate and peer support for children facing a life-limiting illness. However, as professionals in the realms of palliative care and hospice we have the ability to change this. I want to encourage you to think about their friends and classmates. Assess what you can potentially do to help, even if it is just a phone call to the school to offer resources. It might just change a child’s life. It could even change your life, I know it changed mine.

References


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Children’s Project on Palliative/Hospice Services
ChiPPS serves as the Pediatric Advisory Council for the National Hospice and Palliative Care Organization.
Learn more at www.nhpco.org/pediatrics
Siblings of kids with chronic illnesses are more likely to suffer feelings of anger, jealousy, depression, and anxiety. They are also more likely to do poorly in school, abuse drugs, and suffer from mental illness as adults (Derouin & Jessee, 1996). The Bus Stop Club, Inc. offers encouragement and support of the siblings of children with chronic illness or developmental, physical, or intellectual disabilities. The overall goal of the Bus Stop Club is to provide emotional and recreational support in a fun and safe environment.

In the shuffle and chaos of caring for a child with a chronic illness or disability, the significance of the impact on the siblings in the family is too often overlooked. The Bus Stop Club was created to answer the need for an expansion in the definition of “family” when striving to provide a comprehensive care program that ensures each and every member of the family remains healthy and well adjusted. It provides a safe and fun environment in which the sibling who does not have special needs is given an opportunity to be a child, to form relationships with peers of similar experience, to address his or her need for information about the brother or sister’s illness, and to receive psychosocial support.

Compared with the parent, the sibling relationship is most often the longest relationship in the family—one which evolves, matures, and changes over time, one in which the roles vary the most. Sibling relationships shape our behaviors, our thinking and our opinions, and our emotions for life. Though there is no denying that parents feel pain both for the ill child and for their own grief, the brother or sister of an ill child feels the pain on three fronts—for their sibling, for themselves, and for the grieving parent. As such, the sibling’s need for information and understanding is often greater than that of a parent’s.

We must not lose sight of the fact that siblings of chronically-ill children or children with a disability are still children; they have yet to gain the life experiences which enable us to put things into perspective, despite how irrational the encounter may be. Many children are either too fearful or reluctant to voice their feelings; they can only express themselves and their emotions through behaviors. Various studies on siblings of children with chronic illness have uncovered adverse psychological outcomes. Common experiences are aggressive behavior, anger, falling behind in school, poor peer relations, feelings of neglect, and negative attention-seeking behavior. Studies have also revealed some long-term complications such as a tendency toward substance abuse and trouble with the law. (Ross & Cuskelly, 2006).

In January of 2005, Dr. Brian Sheridan, a third-year pediatric resident at the Children’s Hospital at Albany Med, launched the Bus Stop Club—a program which would allow for primary consideration of the well child in the comprehensive care of chronically-ill children. Dr. Sheridan’s insight into the tremendous impact the disease process has on the family as a whole began while working as a camp counselor at Camp Nassau, a YMCA-directed day camp. Throughout his ten year annual summer commitment, he was given the opportunity to work with chronically-ill children. Twelve years later, and nearing completion of the third year of his pediatric residency, he has dealt first hand with the myriad of challenges faced by not only the inflicted child, but the parents and siblings as well. He recognized the parents of chronically-ill children have benefited tremendously from this heightened awareness and family-centered philosophy in providing comprehensive care for the whole child. His goal, however, was to establish a program solely for siblings—one that would provide support through preventative intervention mechanisms designed to enhance sibling adaptation and enable them to remain emotionally healthy and well-adjusted in order to cope with one of the worst hardships any member of the family can endure.

The Bus Stop Club program is held at eight different locations in the Albany, New York, area. Each monthly session lasts for about two hours. The first portion of the session is for the children to enjoy refreshments, meet the other participants, and settle in. The session begins with therapeutic type activities which may involve drawing or painting, role playing, or a game. The activity incorporates a
theme and the child is given the opportunity to explore and expose his or her feelings about the given topic. The themes employed range from the concept of illness and the disease process that is affecting a brother or sister, changes in the family, feelings about relationships with the sibling, and how to cope with feelings they are not able to put into words. On occasion, a community visitor such as an art therapist or music therapist may join the session and facilitates the group as a whole with a therapeutic activity. Often the second half of the session simply provides an opportunity for these children to take part in “typical” childhood activities such as a basketball game or a swim.

In addition to the monthly sessions, Bus Stop Club also provides Family Events. Family Events include the entire Bus Stop Club Family to participate in outings such as a three-bus move to Six Flags, New England, a family BBQ, tickets to the Siena Men’s Basketball Game and Tri City Valley Cats Game, to name a few. In addition to the monthly sessions being free of charge, the Family Events are also free to the Bus Stop Club Families.


Interested persons seeking additional information concerning The Bus Stop Club program should contact Angela Tobin at angela.tobin@busstopclub.com

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These books and resources are meant for use by siblings who have a brother or sister with a complex medical condition or some type of special healthcare need, or who has had a brother or sister die. The majority of these resources are specific to siblings, while some of the bereavement-related books are more general in their discussion of life and death. However, this is not a comprehensive list. For other books beyond those cited here, several websites have been included in this resource list which may provide some additional suggestions.

**BOOKS FOR SIBLINGS**

**Younger Readers (Pre-school/Elementary School)**

**After a Death: An Activity Book for Children**  
By Amy Barrett Lindholm  
Ages: 5-12 years. An easy-to-use workbook for children who have experienced a death, with activities and tips for navigating all that changes at school, home, and with friends when someone has died.

**All Shining in the Spring: The Story of a Baby Who Died**  
by Siobhan Parkinson  
Ages: 8 and under. The story of a boy, Matthew, awaiting the birth of his baby brother/sister, until the family discovers the baby is not growing properly in his mom and won’t be able to live after it is born.

**Always my Brother**  
by Jean Reagan  
Ages: Grades 2-5. A sister, Becky, tells the story of her brother’s death and how it impacted her and her family. In time, she realizes her brother would want her to get on with her life and to find happiness again even though he is no longer here.

**Badger’s Parting Gifts**  
by Susan Varley  
Ages: 4-8 years. Badger’s friends are saddened by his passing, but they realize that he lives on through their gifts of kindness and their happy memories of him.

**Becky’s Story**  
by Donna Baznik  
Ages: 4-7 years. Six-year-old Becky feels left out when her brother is in a bad accident and receives all her parents’ attention.

**Ben, King of the River**  
by David Gifaldi  
Ages: 5-8 years. Explores the mixed feelings and emotions of an older brother and his experiences with his developmentally-disabled sibling on the family’s first camping trip. Includes a page of tips for siblings of kids with special needs.

**Healing Your Grieving Heart for Kids: 100 Practical Ideas**  
by Alan Wolfelt  
Ages: 6-12 years. In simple, straightforward text, this book teaches children about grief while validating that their feelings about losing someone they loved are normal, and necessary.
Help me Remember: A Storybook for Children and Families Coping with the Death of a Baby
by Nivea Castaneda, Veronica Droser, Kate Hoyt, Jeni Hunniecutt, Jessica Johnson, BenBoyce, Emily Krebs and Melodee Sova
Ages: Elementary school. This book that tells the story of three children whose families lost babies, using research-based insights and coping tools to help children and families experiencing the death of a baby.

Hi, My Name Is Jack
by Christina Beall-Sullivan
Ages: 3-12 years. Written specifically for healthy siblings of chronically ill, disabled, or dying children; addresses the feelings of the healthy siblings.

I Am the Big Sister Now
by Michelle Emmert
Ages: Elementary school. A nine-year old girl, Michelle, talks about her life—the happy parts and the challenges—as the "older sister" to her older sister who was born severely disabled with cerebral palsy.

I Know I Made it Happen: A Gentle Book about Feeling Guilty
by Lynn Blackburn
Ages: Preschool-Elementary. This book address typical feelings of guilt siblings may experience when a brother or sister becomes injured or ill and provides support and understanding.

I Miss You: A First Look at Death
by Pat Thomas
Ages: 4-8 years. A book that helps children learn it’s OK to express their feelings when a close friend or family member dies. It sensitively reassures and validates that grief and loss are normal feelings when a loved one has died.

Just Because
by Rebecca Elliott
Ages: Elementary school. A touching story of a younger brother who describes his love for and friendship with his sister with special needs.

Lifetimes: A Beautiful Way to Explain Death to Children
by Bryan Mellonie
Ages: 5-8 years. A moving book that helps explain the concepts of life and death in an age-appropriate and sensitive, thoughtful way with an underlying theme that all things—plants, animals, people—all have their own lifetimes to live and eventually die from.

Lost and Found: Remembering a Sister,
by Ellen Yeomans
Ages: 4-8 years. Elementary school. Story of a girl whose sister, and only sibling, died and her search for her sister, and for understanding, after her death.

Mori’s Story: A Book about a Boy with Autism
by Zachary Gartenberg
Ages: 7 and up. This is a book written by ten-year-old Zachary about his brother who has autism. It discusses how his brother’s condition, and his parents’ constant attention to him, impacts him, and his entire family.
My Brother, Matthew
by Mary Thompson
Ages: 4-11 years. A fictional story that offers a sibling’s point-of-view of having a brother/sister with a disability and the worry, impatience, feeling left out, and being talked down to by adults that well siblings often experience. Also shows how the two brothers do also create a lasting bond.

Princess Pooh
by Kathleen M. Muldoon
Ages: Elementary school. This book tells the story of a girl who is jealous of the “royal” treatment her sister gets in her wheelchair, until she tries the chair out herself and realizes it is not any fun.

Sara’s Secret
by Suzanne Wanous
Ages: 7-9 years. A realistic depiction of how a girl loves her little brother, yet she wants to keep it a secret at school that he has cerebral palsy and mental retardation.

Saying Goodbye
by Jim and Joan Boulden
Ages: 5-8 years. A book and workbook with color-in cartoons, drawings, and activities which present death in a gentle, non-threatening way, while helping younger children understand the finality of death and the feelings associated with this kind of loss.

Sometimes
by Rebecca Elliott
Ages: Elementary school. A story of how siblings support each other even when one of them has to go to the hospital and be admitted for a stay, which can be a scary, intimidating place. (Sequel to Just Because.)

Stacy had a Little Sister
by Wendie Old, Christy Grant, and Judith Friedman
Ages: 4-7 years. The story of an older sister whose baby sister dies unexpectedly of SIDS and the wide range of emotions the whole family experiences as they grapple with this difficult loss.

The Empty Place: A Child’s Guide Through Grief
by Roberta Temes
Ages: 4-10 years. Story of a nine-year old boy whose big sister dies, leaving him confused, angry, and afraid and his parents grieving and distant. A counselor steps in to help them all cope and heal.

The Fall of Freddie the Leaf
by Leo Buscaglia
Ages: 4-8 years. A very simple story of a leaf named Freddie and his fellow leaves and how they change through the seasons, eventually falling to the ground with the winter’s snow, illustrating the delicate balance between life and death.

The Purple Balloon
by Chris Rashcka
Ages: Grades 1-4. A moving and sensitive book about death addressing the messages that talking about dying is hard and dying is even harder, but that there are many people in children’s lives who can help them during these losses.
There’s a Little Bit of Me in Jamey
by Diane Amadeo
Ages: 6 and up. Common feelings of being frightened, confused, and neglected among siblings of children with cancer are explored in this story, which includes a brother finding comfort in donating his bone marrow to his sibling.

The Special Brother: A Sibling’s Story
by Karen Waters
Ages: Kindergarten through 6th Grade. The story of how little Ryan’s life changes when his baby brother comes home from the hospital with a lot of needs—special feedings, loud machines, and lots of tubes—requiring his mom and dad to spend more time with his brother, than him. Helps siblings to see that even with challenges like this in the family, they are still a family.

Views from Our Shoes
By Donald Joseph Meyer
Ages: Grades 4-6. A compendium of 45 siblings aged 4-18 who share their experiences of what their lives are like living with a brother or sister who has a disability, allowing the young readers to see there are others, like them, living in similar situations with their siblings.

We’ll Paint the Octopus Red,
by Stephanie Stuve-Bodeen
Ages: 3-7 years. Touching portrayal of a six-year old, Emma, and her and her family’s adjustment to having a baby brother born with Down syndrome. The book also includes answers to siblings commonly asked questions about Down syndrome.

What About Me? When Brothers and Sisters Get Sick
by Allan Peterkin.
Ages: 4-8 years. Story about a confused young girl who experiences a range of mixed emotions and hurt feelings when her young brother goes to the hospital for a long stay.

What About Me?
by Brenda Lizzett Valencia
Ages: Elementary School. A story about how a girl feels left out because of her parents’ care of her special needs brother and how communication between the parents and the girl helped.

by Michaelene Mundy
Ages: 6-9 years. This book addresses a series of topics children often have related to death and funerals including “Why Do People Die?”, “Does it Hurt to Die?”, etc. A helpful and truthful guide.

When Dinosaurs Die: A Guide to Understanding Death
by Laurie Krasny Brown
Ages: 5-8 years. A book with brightly colored artwork that simply describes the feelings people may have when someone dies while offering ways to honor and remember that person. The book is done in a series of kids’ questions like “Why does someone die? under the guise of dinosaurs as the book’s characters.

When Molly was in the Hospital: A Book for Brothers & Sisters of Hospitalized Children
by Debbie Duncan
Ages: 3-12 years. Heartwarming story of Anna’s little sister, Molly, who has been sick and then had to have an operation and stay in the hospital for a while. Written from Anna’s point-of-view about what it’s like to have a sister in the hospital. Based on a true story.
When Someone Has a Very Serious Illness
by Marge Heegaard
Ages: Elementary and Junior High. A workbook resource that helps children learn about illness and coping strategies when they have a seriously-ill family member. It also encourages them to draw about their feelings and experiences.

Where's Buddy?
by Ron Roy
Ages: Grades 3-5. This fictional story tells of a boy who has diabetes and who has to give himself insulin shots. While staying with a friend’s family, he turns up missing and the friend must find him before he goes into diabetic shock.

Where's Jess: For Children Who Have a Brother or Sister Die
by Marvin Johnson
Ages: 3-6 years. Story of a young sibling who has a baby sister die. Helps explain this sibling death to the very young in age-appropriate ways (although some reviewers dislike the reference to having “died” so many times in the book).

Older Readers (Junior High/High School)

A Birthday Present for Daniel: A Child’s Story of Loss
by Juliet Cassuto Rothman
Ages: 9-12 years. The story of Ellen, who had a brother who died, and her sharing of how his death has changed her personal and family dynamics. The story explores how to remember the birthday of this deceased sibling with suggestions from bereavement counselors on the topic.

A Real Christmas This Year
by Karen Williams
Ages: 9-15 years. Twelve-year-old Megan wants a normal social life, but although she loves her little brother with special needs, his disabilities make her life difficult.

Are You Alone on Purpose?
by Nancy Werlin
Ages: 10-14 years. Alison doesn’t like Harry because he’s rude and teases her autistic twin brother until the two become friends after a diving accident, which leaves Harry in a wheelchair.

Barry’s Sister
by Lois Metzger
Ages: 9-17. Fictional story about a 12-year-old girl and her wide range of feelings about her new baby brother who has cerebral palsy.

Being the Other One: Growing Up with a Brother or Sister Who Has Special Needs
by Kate Strohm
Ages: Teens & Adults. Based on interviews conducted with siblings of all ages with a disabled brother or sister, the author explores the emotional challenges and feelings the well siblings face and provides valuable coping strategies and encouragement for navigating all of this. The book includes writing exercises and resources.

Fire in My Heart, Ice in My Veins: A Journal for Teenagers
By Enid Traisman
Ages: Teens. Helps teens self-facilitate their grief process by providing templates which encourage them to write letters, copy down relevant lyrics, write poems or songs, talk to the person who had died via writing/journaling, etc.
Grieving the Sibling You Lost: A Teens Guide to Coping with Grief and Finding Meaning after Loss by Erica Goldblatt Hyatt & Kenneth Doka
Ages: Teens. A compassionate guide for teens who have lost a sibling, written by a psychotherapist specializing in teen and adolescent bereavement.

Healing Your Grieving Heart for Teens by Alan Wolfelt
Ages: Teens. A user-friendly book for teens that helps teens explore their feelings of grief and loss through healing activities that help to reduce the anxiety, confusion, and personal loss teens can feel. The book helps to explain that teens should not be afraid of their deep, and maybe sometimes, uncontrollable emotions, after the loss of someone they know.

Living with a Brother or Sister with Special Needs: A Book for Sibs by Donald Miller & Patricia Vadasy
Ages: Elementary through High School. Many specific disabilities are discussed, sibling questions and emotions are addressed, and suggestions are offered on how to make life easier for the whole family.

My Sister Annie by Bill Dodds
Ages: 8-15 years. This is the story of a twelve-year-old who has a sister with Down syndrome and what struggles the well sibling experiences herself, and as a sister trying to accept a sibling who is “different.”

Oh Brother!: Growing up with a Special Needs Sibling by Natalie Hale
Ages: 9-12 years. The book provides examples of what it is like to live with a sibling who has special needs, as well as self-help guidelines and coping tools for the well siblings.

Rules by Cynthia Lord
Ages: Junior High/High School. Story about a twelve-year-old girl who has a brother with autism and how it feels to have the whole family revolve around him and his disability and question what is normal in this coming-of-age novel.

Special Siblings: Growing Up with Someone with a Disability by Mary McHugh
Ages: Teens & Adult Siblings. This book shares what the author has learned about growing up with a sibling who had cerebral palsy, and what 100’s of others have learned about having a special sibling and all the feelings that go with that—anger, guilt, love, and pride.

The Sibling Slam Book Edited by Don Meyer
Ages: Teens/Young Adults. Real teenagers take a very honest look at their lives and experiences of having a sibling with disabilities. It’s done in question format with the teens providing answers to questions about living with their special needs siblings. Responses represent a range of complex, and conflicted feelings/opinions that help to reassure readers that they are not alone in these feelings.

The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults with Disabilities by Don Meyer
Ages: Teens and Adults. A book that addresses the biggest concerns/worries that siblings who have brothers/sisters with special needs biggest have including who will care for their siblings in adulthood, guardianship, medical and legal issues, government benefits, and more. Also covers how these decisions can/will impact their lives and how to navigate this journey and plan for the future.
The Summer of the Swans
by Betsy Byars
Ages: 8-12 years. A 14-year-old girl is trying to cope with being a teen and all that brings until her mentally handicapped little brother gets lost, and she realizes what’s most important in life and how much she loves her brother, despite the hardships he brings to her life.

Thin Air
by David Getz
Ages: Grades 5-8. This fictional story depicts a sixth grader who struggles to be “normal” and stay in regular classrooms with his peers while coping with his nearly daily asthma attacks and the attention of his overprotective brother.

Tru Confessions
by Janet Tashjian
Ages: 9-12 years. A fictional diary of a twelve-year-old girl’s take on her everyday life of wanting to host her own TV Show and cure her twin brother of his disabilities.

Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs
edited by Donald J. Meyer
Ages: 7 and up. Forty-five children aged 4-18 contributed to this book. They share their experiences as the brother or sister of someone with a disability—the good and the bad, as well as many thoughtful observations.

What is Goodbye?
by Nikki Grimes and Raul Colon
Ages: 8-12 years. The story of two siblings who are grieving the loss of their older brother, and how it has affected their family, as written through a series of 26 poems all told from the siblings’ perspectives.

Weird is Normal: When Teenagers Grieve
by Jenny Lee Wheeler
Ages: Teens. A self-help book written for grieving teens by a grieving teen who lost her dad to cancer at 14. The book helps to validate for teens they will grieve differently from adults but that it’s OK for them to grieve in a (non-harmful) way that works for them.

Welcome Home, Jellybean
by Marlene Shyer.
Ages: 9-15 years. Story of a 12-year old boy whose 13-year old sister with special needs comes home to live with the family after spending most of her life institutionalized. Shows the family dynamics of how he, and his family, dealt with her being at home and the impact caring for her had on their lives.

All Ages

Brothers and Sisters Together: A Workbook for Siblings of Siblings who are Sick
by the NIH Clinical Center.

It Isn’t Fair!
Edited by Stanley D. Klein and Maxwell J. Schleifer
Ages: All ages. Excerpts from The Exceptional Parent magazine which presents a range of feelings and situations brothers and sisters may experience when they have a special needs sibling. Includes looking at siblings’ frustrations, powerlessness, jealousy, guilt, and worries.
Special Brothers and Sisters: Stories and Tips for Siblings of Children with Special Needs, Disability, or Serious Illness
by Monica McCaffrey and Annette Hames
Ages: All ages. A compilation of real-life stories from brothers and sisters aged 3-18 with a sibling who has special needs, a disability, or a serious illness about what it’s like to live with this sibling. Comes with tips to help the well siblings cope, as well as a kid-friendly glossary that explains their sibling’s disability and/or medical condition(s).

The Invisible String
by Patrice Karst
Ages: All ages. A heartwarming book that reassures children (and adults) who may suffer from “separation anxiety” that they are never really alone from those they love and reaffirms children that love binds and connects all of us in the good and challenging times.

The Next Place
by Warren Hanson
Ages: 5-and up. An inspirational journey of hope, peace, and comfort, to a place where earthly pains and hurts are left behind, portraying the concepts of timelessness, love, and eternity.

WEBSITES FOR SIBLINGS

Band-Aides & Blackboards Website
While primarily a website for the children with complex medical conditions, it does offer some help and resources for the well siblings as well.
http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/sitemap.html

Courageous Parents Network
This is a website for, of, and by families of very sick children. It provides education, peer support and much more. It has a series of videos developed for siblings around the topics of creating memories of their brother/sister, coping tools for the well siblings, etc.
https://courageousparentsnetwork.org/

Sibling Support Project Organization and Website
This is the first national program dedicated to the concerns of brothers and sisters with special health, developmental, and mental health conditions. They provide resources, host online groups, and present workshops. They also work in communities to start and run Sibshops—peer support groups for school-aged brothers and sisters of kids with special needs.
https://www.siblingsupport.org/

To find a Sibshop program near you
https://www.siblingsupport.org/about-sibshops/find-a-sibshop-near-you

SibTeen is a Facebook group run under the Sibling Support project where teenage siblings of people with disabilities can connect with other teens in similar situations. It is a closed Facebook group which provides peer support for these siblings. It is supported by the Sibling Support Project.
https://www.siblingsupport.org/connect-with-others-sibs/meeting_other_sibs_online/sibteen

SuperSibs Organization and Website
SuperSibs is a program of the Alex’s Lemonade Stand Foundation, which is committed to helping comfort, encourage, and empower siblings when a brother or sister has cancer, so they can look forward with hope and courage. Learn more at: SuperSibs.org
https://www.alexslemonade.org/campaign/supersibs-sibling-support-childhood-cancer-families
SuperSibs also have a dedicated webpage for hospital professionals:
https://www.alexslemonade.org/campaign/supersibs/hospital-professionals

WEBSITES FOR PURCHASING SIBLING SUPPORTIVE CARE BOOKS & FOR FINDING OTHER BOOKS OF INTEREST

Amazon
Amazon has an extensive selection of many of these books, and others, related to siblings living with brothers/sisters with special healthcare needs, and death/dying age-appropriate for a wide range of children’s ages.
www.amazon.com

Centering Corporation
The Centering Corporation is a non-profit organization dedicated to providing education and resources for the bereaved. Their website carries their own self-published books, as well as thousands of others written by other publishers. They carry children and teen grief resources, infant loss resources, newborn intensive care resources, among others.
https://centering.org/

Compassion Books
Compassion Books carries over 400 professionally-reviewed titles of grief/bereavement resources for people of all ages, including children, to help them grow through the losses they experience in life. They have offerings specifically for children, and separately, teens.
http://www.compassionbooks.com/

Healing Stories: Picture Books for the Big and Small Changes in a Child’s Life
By Jacqueline Goldring, PhD.
Provides information about resources by way of picture books to help children through the life challenges they face, from the everyday to major trauma. Includes grief and loss. All books have been carefully selected by a psychologist who works extensively with children.
http://healingstoriespicturebooks.blogspot.com/
THE LIVES AND DEATHS OF TWO CHILDREN: THE GRANDPARENTS' ROLE

Gay Lord
Hayden and Cameron's Grandmother
gbirdlord@gmail.com

When our first grandchild was born I wrote her a letter quoting words I had heard the day she was born: “May the bright morning star rise in your heart.” Her Grandfather Charlie and I subsequently celebrated the births of six more babies. I included these words in the welcome I sent to each new child. Our first grandchild is now in college; the fourth and fifth born are now in high school, and the seventh, born to our daughter and her partner, is now in grade three.

The second and third in the order of our grandchildren are a boy, Hayden, born in April 1988, and a girl, Cameron, born in May 1999, each born to one of our identical twin boys and his wife. These babies were born with Tay-Sachs disease. “The bright morning star” was certainly a part of their short lives because of the care and love they received from their parents, their Aunt Deirdre (the boys’ younger sister), and three sets of grandparents. It is their lives, and their effect on me and my husband, that inspires my story. Our twin sons and their wives, unknown to any one of the four, each carried the defective Hex-A Tay-Sachs gene. Our sons carried a mutation of the gene which was unknown at the time, as did our daughter-in-law and her mother. For this reason, these babies died from what is known as The Lord Mutation. I am the carrier in our family and one of the twins’ mothers-in-law also carried an unknown strain of the disease (not the Irish, Cajun, French Canadian, or Ashkenazi). When both parents are carriers (one wife carried the Ashkenazi strain), each child has a 25% chance of having Tay-Sachs and a 50% chance of being a carrier of the disease.

Hayden Lord has a complicated medical history because he received three different diagnoses before the doctors, with significant help from his physical and practical therapists, arrived at the final dread decision. At Hayden’s 12 month physical exam he was said to be 6 months “developmentally delayed.” He had a beautiful celebratory birthday, with other children he had played with over the months. It was so typical of his adoring parents to give him a “normal” celebration. It did not matter that he could not sit up yet or crawl. He could still have his first bite of chocolate cake and share his inimitable giggle with the other children. Several months later, the neurologist corrected this diagnosis to say that Hayden had cerebral palsy, mainly affecting his limbs. While Grandfather and I were saddened by this news we felt encouraged when we read every word that lay people could find, and learned that CP does not actually become “worse” with age. The limitations a person receives in the beginning do not change. Nonetheless we were affected by the news. We cried and tried to comfort each other, wondering what his actual “limitations” would be? Every time I passed a school playground I peered into the groups of children, hoping to spot a “disabled” child who was happily playing with other children. How badly affected would he be? Would he be able to catch a ball or go trout fishing with his father and mother using the fly rod he had gotten at his baptism?

After the CP diagnosis the doctors recommended that Hayden have physical and occupational therapy. Twice a week he had sessions with therapists who worked with rolling balls and stretching, holding different objects, blowing bubbles. Alison, Hayden’s mother, made a beautiful chart to record a detailed account of the exercises, and the numbers of repetitions he accomplished. We tried to learn these routines. Usually we were not able to be helpful because Tim worked so diligently, getting up especially early before work, then working again when he came home, and Hayden got too tired to work more than a couple of times a day. In the few weeks after the PT began, his parents thought Hayden seemed more active and able to move his limbs. I thought this was proven when I watched this child, who could not sit or crawl, determinedly pull himself, crabwise, towards two handles he could see on a chest. He then tried to pull himself up repeatedly until, exhausted, he fell back to the floor.

Several months later, Hayden’s parents assembled the four therapists who had been working with him to assess his progress. It was the therapists who gave the opinion, by stating that the little boy was actually
regressing, that there was a need for another visit to the neurologist. The neurologist sent the family to an eye specialist, who discovered the dread "scarlet red spot" in his eye, a defining mark for the diagnosis of Tay-Sachs disease.

Shortly after the diagnosis, Tim and Alison invited both families to be with them for the weekend. Tim’s brother, Charlie, was there. His wife Blyth, now pregnant herself, was not able to come. We realized, more than ever, in spite of this devastating news, that Hayden’s life would be as comfortable, as joyful, and as fully loved—and lived—as it could possibly be. As grandparents, all four of us were committed to helping achieve this potential. After our dinner on that night in November 1999, Grandfather Charlie and I walked son Charlie home to the place where he was staying. As we turned to go, I reached up to give our son a hug. I said: “I hope you never have to see your adult child suffer.” It was a terrible realization that we could no longer be the “fixers” of children’s problems. The feeling of that power embedded in parental spirits was gone. I had no idea how tragically prophetic my words to our son would be.

Immediately, knowing that, as an identical twin, Charlie would be a carrier of the disease, Blyth went for the test. Only a short time after having heard about Hayden, when Blyth found that she too tested positive for Tay-Sachs, Cameron was taken to be tested. Ironically, not long after Hayden’s parents heard the news in New York, Charlie and Blyth were in their pediatrician’s office in Cambridge. They learned then that Cameron, who had been developing perfectly normally as most Tay-Sachs babies do in the first 6 months, was also afflicted. Later, in a video made for distribution to pediatric departments in medical schools, this doctor expressed the anguish he felt having to tell parents that “a perfect 6 month old” would regress steadily and not live to be more than a few years of age.

It was at this point that Grandfather Charlie and I finally found a therapist. We had been interviewing people for a couple of months and were pleased to have found the wonderful woman who would be with us throughout this journey of anguish, as we saw two babies and their parents move on through life and towards the inevitable deaths of the little children. We now had someone who helped us cope with the times of anguish and the questions of how to help and how to care for ourselves and each other.

In the next weeks, all four parents decided that they would care for the children at home, in the most comfortable, pain-free environment possible. All four wanted to avoid hospital care completely. Tim and Alison had experienced the hospital only once when Hayden had pneumonia. The noises of bells and alarms and cleaning implements and other distractions and unfamiliar hands and movements cause Tay-Sachs babies, who never lose their “infant startle reaction,” to be miserable. When cared for quietly by people who are familiar to them, babies with the disease, are generally calm and gently responsive, rarely screaming or agitated. Cameron’s father said that he wished for her “an arc of life, with a beginning, a middle, and end, all filled with music, "play," sun, and nature, using every palliative measure possible. Both families agreed that, when the swallowing reflex began to fail, as happens with Tay-Sachs infants, there would be no feeding tubes, only home-made healthy food, given with the most natural feeding devices available while being held in a parent’s arms. Both families put ample queen beds in the babies’ rooms so that a parent or grandparent, brother or sister could spend the night with them, for warmth and companionship, to calm a seizure or, perhaps, to suction them if needed. Cameron’s uncle made a special low chair with a table attached so that Cameron could easily reach and play with her stuffed animals toys and books. This was the first destination for three-year-old Taylor when she ran in after school to be with her sister. It is hard to say enough about Charlie and Tim’s sister, Deirdre who was there in Boston and New York whenever most needed. She coped with crises of needed medication and sudden emergencies. And she took from the rest of us, some of the most painful end-of life burdens, which she would not let the parents or grandparents bear.

Tim and Ali andy had a group of friends who wanted to help and were enlisted to take turns on Thursday nights to be with baby while he slept, so that the parents could have a “date night” alone.

Our children found ways, often with the help of therapists, to do the most for these children. Now, what could the grandparents do to be helpful to these families?
We began by saying that we would come to them any time they needed extra hands. All four parents were fortunate enough to be able to continue with their jobs in both Massachusetts and New York, where insurance paid for child care. However they did need respite from the intense involvement with the care of children who needed constant care, attention, and whose complex needs were ever changing. So we did go to stay. We went to help with feeding, to go for walks in good weather in the complex carriages designed for babies with these special needs. We read aloud and sometimes slept in those big beds next to the little ones. At first I felt insecure with Cameron at night, fearing that I might disturb her sleep or be unable to do the small things needed during the night: suctioning to remove mucus, calm her after a seizure (which we had been taught to do), or turn her to a more comfortable position. These nights became an important part of the wonder of being in the loving world of these families.

We tried to find ways that the parents could get away for time both with, and occasionally without, the babies. On weekends when they were away, we stayed in the apartment and helped the baby sitter for a couple of days. One winter we found a friend’s house in Florida where each family could go for a week. The house had a heated pool where Hayden spent many hours in his enormous “treatment” pool. For Cameron’s family that cold Florida winter did not allow for swimming though watching the waves and escaping New England winter gave the parents a break.

Each year the National Tay-Sachs organization hosted a conference in a different part of the country for families with children affected with the disease, and their siblings. Available child care gave families time to compare issues and treatments with others, and to learn about current research into possible treatments and eventual cures for the disease. At meetings for the attending grandparents, we learned that not all grandparents were willing to be as involved as we were. Some were hesitant and afraid, a few were resentful of the disease to the extent that they lost contact with their children. These children suffered the loss of both the emotional and practical help that grandparents can give. How wonderful it was that, in our case, all three pairs of the grandparents were quite close. We have them to thank for wonderful times together.

Another way to help the parents was to accompany them to doctor’s appointments. One visit was particularly relevant for us. We were with Dr. Gold, an elderly man with a shock of silver hair and large hands that were both strong and soothing. He had been a pioneer in the care of Tay-Sachs babies soon after the disease was named for the two doctors by whom it was identified. When he came back into the room, after examining Hayden, where we four were waiting, he turned to Grandfather Charlie and me. “How do you two grandparents feel?” Our answer: “We are proud of our children.”

Hayden died in December 2000, with family coming quietly in and out of the apartment to be with his parents. Cameron died in April 2001, four days after a dancing 2nd birthday party, having been surrounded with family, friends, and flowers.

We thought that the most important things we could do for our children, and for ourselves, were to find all the occasions we could to comfort, hold, and care for the babies, to know their love, and to recognize them as individuals. These little beings, like all humans, were quite different from each other. Hayden was strong, solid, determined, and funny. His father once said that when he looked at Hayden he saw his brother. Cameron was alert from birth, never taking her eyes away from the person she was with; and she was gentle, delicate, peaceful, and aware. I thought she would grow up to be kind, as well as competent like her mother. These children gave us so much more than we could give them.

Wordsworth said this in “Ode to Immortality”

... “But trailing clouds of glory do we come
   From god, who is our home?
   Heaven lies about us in our infancy! “...
Sudden Infant Death Syndrome: For Grandparents . . . A “Double” Grief

First Candle/SIDS Alliance

From the moment you became a parent yourself, you have sought to protect your child from the pain and sorrows in life. Mostly, you have been successful, you've had the ability to solve problems, the power to lessen hurts.

Suddenly, your child is facing a pain far deeper than any other pain in life. It may be deeper than anything that you have ever experienced, or perhaps you can understand this sorrow because you, too, have lost a child.

Either way, you are now experiencing a variety of emotions: helpless-ness, frustration, grief, guilt, and anger. You are suffering a "double grief. "You are grieving for your grandchild, all your hopes and dreams have been shattered, your "promise" of immortality has been broken. You had wondered if he or she would "favor" your side of the family, wondered what he would "become," and had perhaps even bought gifts for "later on" (like that first tricycle or that special doll). Your grief may not even be recognized by your own child, but you are, most definitely, entitled to it. Grandparents are often referred to as "the forgotten grievers." You had a special relationship with your grandchild—one of unconditional love unhampered by parental responsibility.

You are grieving just as deeply for your own child. You feel frustrated and helpless because this is one pain that you can't "just kiss away". All the little ways that you had to coax a smile from that child are useless now, all the magic words that used to solve the problems are empty. You can only sit by, offer support, and watch your child learn to live with this loss.

Grandparents often think that “they should cope better, have all the answers, control the situation and be an example. When all that they have offered: advice, financial aid, baby-sitting, experience, and help, is not accepted, asked for, or is even rejected, they feel guilt, frustration and anger.”

Guilt and anger. One often causes the other, soon the two are so inter-mingled that it is difficult to determine where one begins and the other ends. Grandparents experience "survival guilt" . . . it seems unnatural that a grandparent live longer than a grandchild, grandparents often express the wish that they "could change places" with the lost child. You may be feeling guilty for things that you didn't do (Why didn't I baby-sit every time I was asked? Why didn't I spend more time with the baby?). It doesn't help to know that you thought you had forever--that time is gone. Perhaps you aren't well, or for some other reason, were unable to see the baby at all.

You may be very, very angry. Angry at God for “taking” the child, angry at the doctors, nurses or paramedics for being unable to save the child's life, angry at your other children whose families are intact (though a common reaction, grandparents feel a great deal of guilt because of this anger.) You might even find yourself angry at your own child if your understanding of SIDS is incomplete and you wonder if there was anything they could have done or should have seen. Finally, you might be angry at yourself as you wonder if your genes or chromosomes were “responsible” for the child's death.

We do not grieve according to the age of a baby. Psychologists have determined that the grief period following the death of a child is between 18 and 36 months. Some of the emotions that your child will have will sound strange to you, some will sound familiar because you will be having similar reactions. These emotions are, however, NORMAL GRIEF REACTIONS. Helping your child to grieve will facilitate your own grief.

Your child will be going through a grief “process”. He or she will proceed through four “stages” (although these stages may often overlap each other during the process): SHOCK and DISBELIEF, SEARCHING and YEARNING, CONFUSION and DISORGANIZATION and RESOLUTION. Normal grief reactions
during these stages can be summarized as follows.

SHOCK and DISBELIEF
The initial “reaction” to the loss is intense and, relatively, short lived; it is the period during which the bereaved seem to be “in shock.” The bereaved parent . . .

- May appear stunned or dazed or may be continually crying.
- May experience intense panic, anger or distress.
- Usually denies death, feels that what is happening is “unreal”.
- Has difficulty concentrating, and normal functioning is impeded.

SEARCHING and YEARNING
This stage is the bereaved parent's attempt to “test reality”. It is the time when parents work through the extent of their responsibility for the death. The bereaved . . .

- May experience restlessness, pronounced mood swings.
- May constantly search for cause of death through questioning and conjecturing (e.g. What if I had checked on her more, had taken CPR, hadn't slept in, etc.? or If only I hadn't left him with a sitter, had been there, had heard him, etc.)
- Yearns for child. May "hear" baby cry or "see" baby in shopping mall.
- May continue to check on baby.
- May be a period of great irritability and anger...at God, at doctors, at parents, other children, spouse, self.
- May experience need to “do something”.

CONFUSION and DISORGANIZATION
Often the most "dangerous" stage, this period will see the highest rate of separation or suicide. The bereaved parent, in the process of reorganizing his role . . .

- May feel empty and helpless.
- May feel deeply depressed.
- May be weak and exhausted.
- May have very little interest in anything.
- May neglect basic needs (may have large weight gain or loss, may have difficulty in going to sleep at night, may have frequent nightmares, may have trouble getting up in the morning).
- May experience somatic complaints (headaches, aching arms, stomachaches).
- May experience panic attacks, may be afraid to be alone, may be overly fearful for spouse or other children.
• May “pretend” to be happy.
• Is beginning to accept the reality of death.

RESOLUTION
As the bereaved parent adapts to the loss of his child and accepts the changes in his life, he...
• Will experience periods of normalcy.
• Enjoys renewed energy and interest.
• Has renewed ability to make decisions.
• Returns to normal eating and sleeping patterns.
• Is now able to remember the child as living—not only at the moment of loss.

Grief is, however, a highly individual process. People do not need to be urged to grieve in some predetermined way. There are tremendous cultural differences in how people will grieve—even a husband and wife will seldom grieve in the same way. The resolution of grief takes a long time: years, not weeks. As parents move ahead in resolving their grief, there will always be setbacks, some triggered by specific events related to the child (birthdays, anniversaries, etc.) and some seemingly unrelated.9

A SIDS death is uniquely difficult because of its very nature. Its suddenness and the lack of answers to important questions intensify the grief reactions. As grandparents, understanding what IS known about SIDS is vitally important.

FACTS ABOUT SIDS
Sudden infant death syndrome (SIDS), or crib death, is defined as the “sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history.”10

SIDS...
• Is the number one cause of death in infants between one month and one year of age. Occasionally, an older or younger child may die of SIDS.
• Is NOT a rare disease. About 3,000 babies will die each year in the United States (less than one per 1,000 live births). SIDS will take more lives than cystic fibrosis, childhood cancer and heart disease, and child abuse, combined.
• Is NOT predictable and NOT preventable. A minor illness (such as a cold) may proceed the death but many victims display no observable symptoms.
• Is NOT caused by suffocation, aspiration or regurgitation.
• Is NOT painful. Death occurs within seconds, usually during sleep.
• Is NOT contagious.
• Does occur in families of all races, religions and living circumstances.
• Is often referred to as “crib death” and is as old as the Old Testament. The term sudden infant death syndrome came into general medical use after 1969.
Probably has more than one cause, although the final process of death is similar in most cases.

As a parent, you want to know how to help your child proceed through the grief process. Your role is to guide and support—and that role will require great patience and understanding. The Compassionate Friends, a support group for parents who have lost children of all ages to all causes, devised a list of "DO'S and DON'TS" for the families and friends of bereaved parents. Their suggestions, along with a few of our own, include:

**DO...**

- Let your genuine concern and caring show.
- Be available...to run errands, to listen, to help with the other children, to do whatever else needs done at the time.
- Allow them to express as much grief as they are feeling at the moment and are willing to share.
- Say that you are sorry about what happened and about their pain.
- Encourage them to be patient with themselves, not to expect too much of themselves and not to impose any "shoulds" on themselves.
- Allow them to talk as much and as often as they wish about their child.
- Reassure them that they did everything they could, that there was nothing that they missed and that there was nothing else ANY ONE could have done to save their child's life.
- Help them let go of the questions and the guilt.
- Remember the child's birthday and anniversaries with the parents.
- Do give special attention to the child's brothers and sisters (they are hurt and confused too and in need of attention which their parents may not be able to give at this time).

**DON'T...**

- Let your own sense of helplessness keep you from reaching out.
- Say you know how they feel unless you have also lost a child.
- Say "you ought to be feeling better by now" or anything else which implies a judgement of their feelings.
- Change the subject when they mention their child.
- Remove pictures of the child from your own home (they need their child remembered.)
- Avoid mentioning the child out of fear that you will remind them of their pain (they haven't forgotten it).
- Point out that at least they have their other children (children are not interchangeable).
- Say that they can always have another child (even if they want to, or can, another child will not replace the child that they have lost).
• Make any comments that suggest that the care given their child at home, in the emergency room, etc., was inadequate.

You can't make the pain go away, you can't bring your grandchild back, but you can help make YOUR child's adjustment to the loss much easier. By grieving together, you reaffirm that grief is normal and that life will go on.

Someday there will be peace again.

References:

5. Gerner, Margaret. “To Bereaved Grandparents”. The Compassionate Friends.

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Commentary by Colleen Pawliuk, Librarian for PedPalASCNET

Trends in Pediatric Palliative Care Research (TPPCR) is a listserv distribution that aims to collect new and exciting research into a monthly list for anyone with an interest in pediatric palliative care. The hope is that these articles will not only contribute evidence to the practice of pediatric palliative clinicians, researchers and trainees, but also spark conversation and debate on these topics. To facilitate this discussion every month a commenter writes a blog post on one (or more) article from the list, often tying it back to their own practice or research. The commentary helps to highlight articles that may be of particular quality or interest.

Creating the list was a collaborative and iterative process. We derived inspiration and sought advice from other librarians and institutions that have experience creating similar lists to learn more about their search strategies and process. Multiple test lists were evaluated and assessed by the clinician-researchers based on their own experience and interests. This was very helpful to me, the librarian, as it helped extend my own understanding of the field, and I was able to edit the search strategies and the way we filter the results based on these discussions.

In the interest of access and collaboration we share our citation list on our blog so others can use or translate the strategies for their own needs (for instance an individual student project or a library working group). As the list has grown, we have extended the scope of databases we search to include a broader range of topics and formats. They include: Web of Science for conferences, Cinahl for nursing and allied health, and PsycInfo for its focus is psychology and social sciences.

Even in a sub-specialty field such as pediatric palliative care, with a small population and a limited research production, it can be difficult to keep up to date with newly published literature. The TPPCR list is filtered to remove articles that focus solely on specific treatments and cures or are localized in a particular place. Instead the focus is on articles that can be used across the population or deal with broader psychosocial themes. Our hope is that everyone who reads the citation list and commentaries finds at least one article that sparks their interest and helps them to engage in the field of pediatric palliative care research.

This citation list is generated monthly by PedPalASCNET to collect new articles in pediatric palliative care research. To see past citation lists and expert commentaries visit our blog.


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ITEMS OF INTEREST

In each issue of our ChiPPS e-newsletter, 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](http://www.nhpc.org/pediatrics). Also, more palliative care resources are available at [www.nhpc.org/palliativecare](http://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**
Join NHPCO Today!
**Individual Palliative Care Membership**
**Palliative Care Group Application** - Save by registering your entire team

2. **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](http://www.caringinfo.org)
     - *When Your Child is in Pain*
     - *Talking With Your Child About His or Her Illness*
     - *Talking to Your Child's Doctor: When Your Child Has a Serious Illness*
     - *When a Child Dies: A Guide for Family and Friends*
     - *Helping Children Cope with the Loss of a Loved One*

   - **NHPCO's Palliative Care Resource Series** now includes pediatric palliative resources such as:
     - *Pediatric Pain Management Strategies*
     - *Communicating with a Child Experiencing The Death of a Loved One: Developmental Considerations*

   - **Center to Advance Palliative Care**: Did you know there are new tools to support your program? CAPC is pleased to announce the launch of three new resources for pediatric programs.
     - **Pediatric Palliative Care Survey in the CAPC National Registry**: Submit your program data now to generate individualized performance reports on program structure and operations, as well as comparisons to other pediatric palliative care programs. CAPC membership is not required.
     - **The Pediatric Palliative Care Field Guide**: A catalog of field-wide program development tools, support sources for field research, and an updated value statement to help programs make the case for pediatric palliative care resources.
     - **The CAPC Pediatric Palliative Care Toolkit**: A collection of new, practical tools and technical assistance for pediatric palliative care programs developed by leaders and experts across the country. Available to members now in CAPC Central.
3. Pediatric Hospice and Palliative Care Training:

- **Incorporating Creative Therapies at Home** Speaker: Sarah Miedel, MS, CCLS, LBS Manager, Therapeutic Activities Department, The Children’s Institute presents Hands-on Breakout Sessions: Music Therapy, Art Therapy, Recreational Therapy, Sibling Engagement Friday, May 12, 2017 9:00 a.m. - Noon Registration and Continental Breakfast 8:30 a.m. - 9:00 a.m. Excel Square at Norwin, South Entrance, Community Education Room 8775 Norwin Ave, Irwin, PA 15642

- **Pediatric Palliative Oncology Symposium:** St. Jude Children’s Research Hospital is hosting its first annual interdisciplinary Pediatric Palliative Oncology Symposium, focused on the comprehensive care of children with cancer and their families; featuring experts and a panel of bereaved parents. Marlo Thomas Center for Global Education and Collaboration June 8–9, 2017 St. Jude Children’s Research Hospital 262 Danny Thomas Place, Memphis, TN 38105

- **The Optum Hospice Pharmacy Services Annual Conference** will be held June 15-16 at the Hilton Columbus Downtown in Columbus, OH. This free two day conference continues to be one of the most anticipated events of the year, providing concurrent educational sessions on both adult and pediatric topics. Participants may choose a free copy of one of the publications: Palliative Care Consultant, 4th Edition; Pediatric Palliative Care Consultant; or Wound Care at End of Life! A discounted room rate is available at the Hilton Columbus Downtown and will be offered until the reserved block of rooms is full or the cut-off date of May 22nd. Make your hotel reservation today by calling 800-445-8667 or visiting https://aws.passkey.com/go/OPTUM2017 and referencing you are with the Optum group. REGISTER TODAY AT: https://UHS.cvent.com/OptumHospicePharmacyServicesAnnualConf

- **8th International Cardiff Conference On Paediatric Palliative Care 26th – 28th July 2017:** This year we will consider the challenge of providing the same standard of care for children and their families in countries across the world, in the face of cultural contexts that can be vastly different in the way they understand medicine, dying, palliative care, ideas of family - and even the way they think of and value children themselves. The theme of the 2017 Cardiff Conference on Paediatric Palliative Care will be Worlds apart: culture and context in caring for the whole child.

- **9th Annual Pediatric Hospice and Palliative Care Essentials, Invitation to Submit Abstracts:** The Texas Pediatric Palliative Care Consortium and Project Joy and Hope are pleased to announce the 9th Annual Pediatric Hospice and Palliative Care Essentials Conference. The PediHOPE draws an interdisciplinary group of attendees composed primarily of professionals who provide care for children with complex medical conditions from across the nation. This includes physicians, advanced practice nurses, nurses, chaplains, social workers, hospice staff, genetic counselors, child life therapists, legislative and policy personnel, administrators, and parents. This year’s conference Creating Balance through the Journey in Pediatric Palliative Care seeks abstract themes aimed at balancing the challenges of caring for seriously ill children and quality of life for families and health care professionals. Submit abstracts HERE
4. **Journal / News Articles**
   - Reimagine Well's Infusionarium is a "Game Changer" for Cancer Patients. Read more [here](#).

5. **Subjects and Contributors for Future Issues of This E-Journal.** For upcoming 2017 E-Journal issues, we plan to address issues related to: Spirituality of Families and the Children Themselves When Faced with Life-Limiting/Life-threatening Illness or Death, Perinatal/Prenatal Hospice & Palliative Care, and Concurrent Care/Waivers. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at christytork@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

6. **Reader's Corner.** Our Reader's Corner columns provide brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric hospice and palliative care, but that may not be known to readers. We welcome suggestions for publications to include in our Reader's Corner and/or summaries and comments on such articles. Please send suggestions to Christy Torkildson at christytork@gmail.com.

7. **The Perfect Mother’s Day Gift**
   Honor your mother or another special woman in your life this Mother’s Day with a donation to the National Hospice Foundation. Mothers are some of the world’s most powerful people. They feed us, teach us and protect us. Most of all, they love us - unconditionally. She learns to survive on little sleep, with enduring strength and a natural ability to multi task, often juggling mountainous workloads and competing priorities. She finds an unending amount of love to share amongst those in her care and knows when it is time to let go and let you discover your own world.
   The National Hospice Foundation invites daughters and sons of all ages to find a new way of honoring mothers this Mother’s Day by making a tax-deductible donation today. And we will send a lovely acknowledgement to the recipient so she will know of your generosity. Mother’s Day is May 14. Make your donation today.

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