Welcome to the 42nd issue of the ChiPPS E-Journal (formerly, the ChiPPS electronic newsletter). This issue of our E-Journal offers a collection of articles that explore selected issues in bereavement and care. These articles offer suggestions for and examples of engaging in the important work of providing pediatric palliative/hospice care. Because this is a huge and very important subject, we have chosen to devote two issues to these discussions. This is the first of those two issues. Even so, we appreciate that no two issues or collections of articles will do justice to this very broad subject area, but we hope that the articles in this issue and in the one that follows it will spur increased awareness and discussion, along with improved implementation or expansion of programs and interventions in this field as a cooperative enterprise with children, adolescents, their family members, the professionals, the volunteers, and the organizations involved in their care. We welcome communications from anyone who has more to offer on these subjects.

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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.
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Issue #42:
Bereavement and Care, Part One
(Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.)

The Loneliness of Suffering  p. 5
Michele Cushatt
We begin this issue with a brief article that reminds us of a fundamental truth: “To live beyond loss comes at steep, steep cost.” One important aspect of that cost is a sense of abandonment and loneliness often experienced by many bereaved persons, including both children and adults. So that hardest thing to do for many, as for this author, is “The choice I make every day to wake up and live.”

Work Spades  p. 6
Amelia Ryan, BA, CCLS
Another source of grief and mourning is the stress often encountered in working with children who have life-threatening or life-limiting conditions and with family members. This article reflects on such work.

Lifetime Warranty  p. 8
Scott Newport
Scott often contributes poems. Here he offers an essay reflecting on the loss of his son and of a misplaced tool. This reflection leads Scott to comment on his new mission in life: “To mentor dads who are in a scary position just like I was in so many years ago with a sick child. I have found life within loss.”

Charlie’s Bonus Round: St. Louis Dad Prepares Daughters for Goodbye  p. 10
Brooke Hutson Gibson
Grief and loss linked to terminal illness do not only follow death; sometimes they come ahead of time. This article describes the work of a bereavement support center for children that helped to arrange a special “prom” night for his two daughters and a man facing the inevitability of his slow-growing brain tumor. After years of interventions Charlie decided to forego further treatment. His special night with his daughters leaves them with magical memories.

5 Ways to Help Parents Who Lost a Child during Pregnancy  p. 13
Jennifer Oradat
Losing a child during pregnancy is a special challenge. But what if the child is a twin? This brief article by a mother who has walked that journey suggests 5 ways to help.

Grief and Bereavement: Developmental Stages  p. 14
Kathleen Davis, PhD, MSEd
Bereavement, grief, and mourning are different for children and adolescents than they are for adults. Many writers acknowledge that by outlining an overly simple and stereotyped description of developmental stages as if they were little more than rigid, successive steps on a ladder. But each youngster is unique and that uniqueness needs to be taken into account in how he or she is approached and understood. Here an experienced palliative care nurse provides an informed introduction to this subject. She concludes that, “Above all else, each child is a unique individual who will process grief in their unique and individual way. Children need a grief guide who will be there to listen, to help them express what they are feeling, and to address their needs.” If we can do this, we will be better able to understand and help grieving children—and we will learn more about ourselves along the way.

Ritual in Perinatal Bereavement  p. 21
Rana Limbo, PhD, RN, CPLC, FAAN
This is the first of three articles on helpful interventions for grieving children, adolescents, and parents. It begins by noting that: “Creating memories that live in one’s heart and mind are ways to find comfort after a child dies. Ritual is a way of making the most of moments that matter.” The article then describes how ritual, in both public and private forms, can help parents, family members, and professional care providers when death occurs in pregnancy or near birth.
Art Therapy with Bereaved Children
Jennifer Lemisch, MA, ATR-BC, LPC
Another important way to help grieving children is to use therapeutic modalities with which they are familiar and which best suit their individual and developmental capacities. This article explains that “Art therapy is a modality which allows for children to receive counseling surrounding their grief, encourages sharing of feelings, and promotes effective coping strategies to manage grief.” An example of a 5-year-old child illustrates how this can work.

Therapeutic Bereavement Interventions for Teens: Bereavement Groups and Camp
Sherry R Schachter, PhD, FT
All interventions intended to support and help bereaved youngsters need to be suited to the specific needs of the youngsters in question. This article describes the activities designed for teens that have been implemented over many years in both bereavement groups and in a week-long day camp.

Reader’s Corner
Suzanne S. Toce, MD
Our Reader’s Corner article in this issue offers short summaries and guides to the intended audience, special qualities, and applicability of two articles on pediatric palliative care in Canada.

Items of Interest
In each issue of our ChiPPS E-Journal, we offer additional items of interest.
I didn't expect the loneliness of suffering.

In all the preparations and appointments and conversations, that part never came up. And yet that part proved equally as powerful and unmanageable as the pain itself.

It's not that friends and family members don't try to share in it. They do—bless them—asking questions and spending long hours listening and attempting to understand.

But I've learned that no matter the hours and days and weeks I invest trying to explain the complexities and consuming loss, I can find no words equal to the task. Try as they might to understand, a witness to a hard journey can't know what it's like to actually walk it. It's like looking at photographs of a marathon and believing you know what it feels like to actually run it.

Instead, from a place of relative distance, the well-intentioned simply see the miracle of life that is you. They see how suffering could've swallowed you whole. And how, somehow, it didn't. For that reason, they don't see reason to mourn; they see cause for celebration.

Still, for the person who suffers, for the one who endured the unthinkable, grief requires a reckoning. The only way to arrive at honest celebration is to, simultaneously, allow yourself honest lamentation. Those who suffer will tell you without hesitation: To live beyond loss comes at steep, steep cost.

Someone recently asked me, "What's the hardest thing for you right now?"

It didn't take me long to answer.

"The choice I make every day to wake up and live."

Yes, there is a deep loneliness in suffering. Whether it's a terminal disease, a chronic illness, the loss of a child, or the irreparable severing of a relationship, suffering brings with it an "otherness." Perhaps that is both the burden and the gift. For in this lonely place we learn how to keep company with others who find themselves there.

For that reason, in this social media world of buffered realities, tonight the truth needed to be said. It's easy to assume that life comes back once the crisis is past. But please know this:

Life never comes back. Never. New life can grow, and I already see evidence of that fact. But new life can only grow as it is watered by grief's tears.

If you know someone who suffers, will you please sit with them in it? Don't try to rush them past their grief and into the safety of your celebration. There is no formula, no math that works in a place of loss. Six months, two years, a decade. For each one the timeline proves different. But to give a griever the grace of your patience and space? That might, in fact, be the sweetest gift of all.

And for my friend who suffers tonight in loneliness, this post is mostly for you. I have no clichés or platitudes or inspirational quotes. You and I both know better than that. I simply want you to know this:

I see you. And I'm with you. As long as it takes.

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I could tell you a million sad stories about a million hard things that happen to kids. And their families. Well, maybe not a million. But eleven years’ worth. I could tell you about horrible, awful things. Worse than you can imagine. Worse than you’ve seen on TV. It would alter your mood. And change the vibe of your get-together, if I’m honest. I know better. I won’t do that. I will listen to you talk of work stories. And I will let you insert hard things for me to hear like “you have such a fun job” or “I could never work in a children’s hospital” or “I don’t know how you do it.”

It really would not be fair to follow up your bad-day-at-work story with one of mine. That’s because when it comes to sad stories, I’ve got a hand full of spades. Every single time. Pretty soon you just won’t want to play with me anymore. You won’t ask about work. It will be the elephant in the room, the one in the corner making herself a drink. Don’t worry, it’s okay. I get it. I do understand. It’s hard for me, too, walking into the hospital on some gorgeous happy sunny days. You never know what you’re walking into. You never know how hard your hands will be squeezed. Or how many times your heart will be flipped upside down. How many screams or cries you will hear. Or how hard it will be to hold back the tears building a sad castle inside. You never know how many times you will need to go to the bathroom. Or how many times you will just have to keep holding it. Or if you will eat anything other than a donut and cheez-its. It’s an unpredictable environment, to say the least.

But, it’s not all ace of spades sad trumping stories. Or none of us would do it. There are victorious, fist-pumping, small miracles happening. All around. I could also tell you of some of the most inspiring stories. The times where I’ve witnessed love in its purest, most raw, and unconditional form. When I’ve held back both happy and sad tears as I left the room to go grab a warm blanket. Or a glass of water for a parent. I can attempt to describe to you the thrill of working on a team where each member excels in different roles, but most have mutual respect and adoration for each other. And every member has the same goal: to help make things better in both gigantic life-saving ways and the seemingly small, dignity reviving ways. We all show up and hope to help kids and families overcome. We aspire to make the world inside a kid’s hospital better.

If I could see that you truly wanted to listen, I would highlight all the joys and all of the many pains. The frustrations. And the necessary humor. Definitely the life-changing moments. The many heroes and heroines. You would hear all about the kids who proudly shouted “I did it!” after completing something really scary and painful. And excruciatingly hard. I wouldn’t forget to tell you of the time when I witnessed a teenage brother sit on the bed and comfort his younger sister in the most inspiring, compassionate way. A way that reminded me of my big brother. Or the time where I stood beside a father who held on so tightly to his daughter’s head and hand, never letting go, as she screamed in pain and begged him to hold her. I think she was begging him to make it stop. To rescue her. But he couldn’t do that, so he did what he could. He held onto her through the hurt.

I would need to tell you of the innocent, gigantic-hearted children who say things like, “I want to stay at your house” or “do you want to go to Worlds of Fun with us?” And of the painful, heartbreaking realizations that tumble out of kids’ mouths like… “He was just a kid. And he died.” I would have to boast
about the littlest interpreters who carry the weight of speaking English to the doctor and Spanish at home. Who speak for their mother or father, all the while trying to play and just be a kid. Just a few weeks ago, one sweet seven-year-old boy fumbled and told me, “I got lost in a word.” How perfect. I knew exactly what he meant.

I get lost in words, too. Especially when I try to explain what working in a hospital is like. Most people have a hard time listening. So I stop talking. I recognize that maybe you just wanted to hear something less heavy. More happy. Lighthearted.

Unfortunately, I think I can usually trump any sad story you tell. That doesn’t mean I should. Or that I want to. I usually won’t. I try to hide what I hold in my hands. And in my heart. Unless I know that you carry a hand of spades, too. I will not unravel in front of you. I will hold my cards tightly. To my chest. You will never know of the faces, the sounds, the room number. The smells. The horror. The memory triggers. I know I can’t tell you about this. If I told you about it, you may not understand. You would wonder how I can talk without sobbing. You would think I’m some sort of sick human being. You may think I just don’t feel anymore. Or that I’m insensitive, maybe calloused. Burnt out perhaps. You may say something like, “I just don’t know how you do it…..how you don’t cry.” You forgot to ask me the question. You assumed that this work doesn’t affect me. Maybe not like you imagine it would affect you. You forgot to ask,

“Do you ever cry?”


I cry as I turn my back to you, quick tears that never exit. I cry in the halls and bathrooms at work. Bent over using the cheapest toilet paper or paper towels to wipe them away. Or in my office. I cry at home in my kitchen into a dish towel or on the treadmill into my t-shirt. I cry in my bedroom into my pillow when my kids are sleeping or getting ready for school. Just because I can stand in this room or tell a story without crying doesn’t mean I don’t feel the utter sense of loss and pain and unfairness that you felt upon first imagining it. I’m only human. I’m actually a lot like you.

We all have different strengths. And different capacities. Limits. Gifts. Yet, we all have weaknesses. Vulnerabilities. Every single last one of us. There is a completely different language that takes years and years to recognize and learn. A language we will never fully understand. And the more time you spend around this unspoken language, the more deeply you feel. In happy or sad moments. It’s the language of hurt. The language of pain. The language of unexpected, life-altering circumstances. It’s too difficult to try and understand in a moment. In a conversation. In a day. It’s much too complicated. It often feels foreign, uncomfortable. You just can’t fathom the all-encompassing, overwhelming, and sometimes heart-stopping beautiful feelings that accompany holding these cards. So, I will nod. Put on my best poker face. And most likely I will never let you truly know what it feels like to work in a children’s hospital. It’s easier for me to just hold my cards closely, tightly, right up next to my beating heart.

This essay was originally published on the blog, Something’s Burning.

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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.
LIFETIME WARRANTY

Scott Newport  
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Last Sunday from the center stage the pastor professed, “You can’t give away what you don’t have.”

Earlier, I was writing a story about losing something I cherished and after hearing those seemingly profound words from the pulpit I scribbled this down. “You can’t lose something you don’t have either.”

I never go to church without my notebook and often write outside the parameters of the sermon. This was one of those occasions.

During the sermon I finished writing the following story.

“Hey Scott, I thought I lost that, you can have it if you like. You could use it in your woodshop.” As I turned toward Dave he kept on by saying, “Maybe it can help with all the handmade gifts you make for families up at the children’s hospital.”

Dave is a large man and works in the automotive industry. I figured it was a real privilege to receive something he thought was lost forever.

As Dave was still trying to peek over the mound of accumulated stuff he repeated, “Scott, as you can see, I have way too much stuff anyway.”

Even though I didn’t think about it at the time, I now realize that losing something you cherish to the clutter of life or losing the ability to own it by giving it away can have two totally different outcomes. But in the end they are both a loss.

After Dave, the homeowner offered me the gift I glowed with excitement. While still on my knees I kept sifting for other possible lost items. The gift was a well-worn, ratcheting screwdriver. The finely crafted black and silver metallic tool was the ultimate treasure because it was a Snap On brand which was way out of my price range and comes with a lifetime warranty.

I was at Dave’s house that day installing a new overhead garage door and because his building was a bit of a mess we had to clean it up first. You know, kids bikes, old exercise equipment, and a pile of tipping, floppy cardboard boxes like the one that gave up the screwdriver. There were even two lawn mowers in there and I believe they both worked just fine. After I installed the new overhead door, I helped Dave jamb everything out on the driveway back into the bloated, one car garage; everything that is, minus one screwdriver.

Over the next year I was always so excited when I was able to use the screwdriver. The tool’s main use was to install fragile brass screws for delicate hinges. The hinges were for the lids of wooden boxes I had made for a few of the kids at C S Mott Children’s Hospital. Most were constructed of reclaimed walnut or mahogany and all had a small sliding drawer lined with soft silver cloth. A few were quite large and were given to families who had lost a child. I called them memory chests.

The best part of the screwdriver was it had a glossy black, removable end cap holding various types of attachments allowing for different size screws.

Unfortunately, a couple of years back on a snowy winter morning here in Michigan I went for the screwdriver. The afternoon before I had applied the final urethane finishes on a couple of the boxes and was ready to install the hardware still protected by tiny clear plastic bags. After searching for about a half-
hour in all the nooks and crannies in my shop, I gave up and anxiously called one of my co-workers and asked if he had used it.

“No Scott, I am not sure I even know about that,” Stew said.

“Are you sure,” I demanded. “I know you cleaned up the shop last time and maybe you just misplaced it,” I begged.

Not only did I now not have that screwdriver, I almost lost a friendship I cherished that frigid day.

Because of my son’s terminal illness and the lack of income I couldn’t replace the lost tool. I did finally find another one on sale at Home Depot of lesser quality; it did just fine.

As my son, Evan, continued to get sicker, we lost him on Thanksgiving Day to the disease monster at the age of seven. Even though our family still endures the grief, we still cherish the seven years we did have because the doctor’s original prognosis was only two.

“Scott and Penni,” the doctors said. “Kids like Evan usually don’t make their second birthday.” I guess that was his way of giving a lifetime warranty of sort.

Now the loss of the tool seems like such a nondescript event. In fact, I don’t think I will ever replace the one I have now with a duplicate like I got from Dave.

Let’s move six years past the loss of my boy, Evan, and I have still not found a replacement that’s, “just fine,” either.

I have, however, found a new mission in life and that is to mentor dads who are in a scary position just like I was in so many years ago with a sick child. I have found life within loss. A gift only Evan could have given me, and that, my friends, is just fine. And I believe that will carry me through the rest of my life.

Looking back now, I hope maybe, just maybe that tool, the lost screwdriver from Dave will turn up somewhere or another, like it did to me and maybe make an impact that will never be lost.

Remember what the pastor said. “You can’t give it unless you have it.” When he said those words he was referring to mentoring. And remember what I wrote down, “You can’t lose something if you don’t have it either.” I guess the lesson is you can sometimes give that something special away, but you will have to do it by losing something you may really love. No matter if it is a fine screwdriver or a son, you will never forget.

I know it’s not a fatherly-like thing to compare my son with a tool. I do believe without both it may have taken me longer to be a bit more OK with my personal loss of having one less family member. The mentoring I do now gives me a joy by allowing me to help the next dad who may one day lose his child too; a lifetime warranty I will never give up.

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“Wow, our lives could have just changed,” said Courtney Beers, after returning home from a trip to the ER with her husband Charlie Kwentus. He was 26, and had suffered a seizure the night before. They thought it was a false alarm until the following day when they received a call from the neurosurgeon that scans revealed a brain tumor.

Webster Groves High School (St. Louis) sweethearts, Courtney and Charlie, had been married just a year. Charlie had earned a degree in Industrial Relations from Rockhurst College in Kansas City and Courtney had graduated from Saint Louis University with an art history degree.

Their friends immediately came together and raised $25,000 to help with Charlie’s first brain surgery. The doctors were able to remove part of the tumor—a Stage 2-3 oligodendroglioma. After the surgery, Charlie began radiation and was told the tumor was slow-growing.

“It was always in the back of our minds, but life seemed to go back to normal for a while and we were able to ignore it,” said Courtney.

In early 2005, the cancer came back. Their daughter Zoe was 3½ and Courtney was five months pregnant with their second daughter, Maren.

In 2011, Courtney reached out to Annie’s Hope – The Bereavement Center for Kids for help in talking with their girls. One of the programs provided by Annie’s Hope is Horizons, which helps children and families grieving an impending death—a family member with a terminal diagnosis. The Horizons Coordinator, Megan Hopkins, and her volunteers meet with the patients’ families in the home or hospital. The personalized and tailor-made sessions focus on memory-making activities, creating keepsake artwork, and talking about fears, feelings, and questions they have about the sickness.

“We are the leaders of the Megan Fan Club!” said Courtney. “She has a wonderful way of walking in the door and assessing the way we’re feeling.”

“I’m not the most communicative and Annie’s Hope has provided a stage for conversations that needed to happen,” said Charlie. “Now it’s Horizons; then it will be Annie’s Hope support groups that will help the girls—a seamless transition…it lets me know they will be alright.”

Through Annie’s Hope and the Horizons program, Charlie, Courtney, and their girls have had a lot of opportunities to share with each other and make lasting memories.
“Charlie has no control of death and what happens after…but through Horizons, Charlie has a chance to answer questions, and say the ‘I love you’s.’ It is so great that the girls have the opportunity, comfort, and foresight to ask [Charlie], ‘what are your three wishes for us?’”

Charlie considers Annie’s Hope and the Horizons program an “amazing gift” to their family as it has enabled them to be more prepared for his death and has provided their daughters with the tools to help them. “We’ve had hard talks, but special talks. I let the girls know I want them and their mom to be happy,” said Charlie. “Horizons and Annie’s Hope…for me, it’s making for a softer landing.”

Between 2005 and 2013, Charlie underwent two more brain surgeries and multiple rounds of chemotherapy.

In May of 2013, Charlie made a choice. No more treatments. He was tired of being sick and tired of living life two weeks at a time. Many family and friends questioned his decision, “Don’t you wanna live?!?” Now they see the “living” he has done since stopping chemo. A good friend told him recently, “I thought you were crazy, but now I understand.”

“Our whole life changed when he chose to have quality of life over quantity—knowing that meant he would have a shorter time here with us,” said Courtney. “And now we see things we would have otherwise missed.”

“I have a whole different outlook since I stopped treatment,” said Charlie. “We call this the ‘bonus round’…Through this journey I’ve learned what is important—Family. I learned to de-clutter my life. It’s made me a better person—I see the good things.”

“It’s taught our girls to see the good in life and the silver lining,” Courtney added. “The kids have been so aware that we are on borrowed time.”

“We would have been totally different people…life would have been all about working and the weekends about cleaning house and laundry,” Charlie said.

Since May of 2013, the Beers-Kwentus Family have been all about being together. They take day trips on the weekends. “I don’t need to go anyplace extravagant,” said Charlie. “I’m of the opinion that if you don’t expect anything, great things will happen.”

This past summer, they went on their “Griswold Family Vacation”—driving 6,600 miles, touring 15 states in the West in three weeks. “Charlie was able to show the three of us places he’s been that he thinks are beautiful and we also got to explore new places together,” Courtney smiled.

When asked if he had a bucket list and what he would still like to do, Charlie said, “There was an absolutely beautiful day when we were in Colorado and I said to the girls, ‘It’s perfect days like this that make me realize there were things on my bucket list I didn’t even know.’”

When Charlie thinks about his legacy and how he would like to be remembered, he said, “I just want to leave behind caring and compassionate people.”

Courtney said Charlie has already taught their daughters to be kind and show compassion by the way he has lived and loved others. “Charlie brings out the best in people. I hope we can still see that for ourselves when he’s not here.”

Courtney’s advice to families who have received a terminal diagnosis is to get help and don’t just treat the illness—take care of your emotions. “I don’t know what we would have done without Horizons. It is great to know that, with the help of Annie’s Hope, other kids make it through the death of a parent and they are okay. For the girls to know they aren’t alone is huge,” said Courtney. “Annie’s Hope and Horizons have changed our life and it’s changed our experience.”
The couple is grateful for the additional time Charlie has had. “Often times, people will hear our story and offer to pray for us—for a miracle. But this is our miracle—we are living it each day Charlie gets to be here with our amazing girls,” said Courtney. “As Charlie says, ‘this has been one heck of a last hurrah.’”

Each year, Annie’s Hope – The Bereavement Center for Kids provides hope and healing to over 3,000 St. Louis-area kids and families grieving the death of someone significant. The program featured in this article, Horizons – anticipatory grief program – helps families communicate feelings with each other, while they build and preserve memories; search for inner peace; explore and identify new, effective, healthy ways of coping; and discover hope for the future. Activities include exploring wishes of the dying individual and implementing meaningful experiences for the surviving children by creating photo albums, quilts, picture frames, video/audio, and creative preservation of memorable items. Annie’s Hope offers all programs at no-charge, including: Horizons, Family Support Groups, School Support Groups, Teen Retreats, and Summer Camps. To learn more, check out www.annieshope.org or call 314.965.5015.

**Editor’s note:** To see a video done by a local television station about Charlie facing imminent death and how a “prom” night out with him was arranged for his 13- and 10-yr-old daughters, go to: https://www.youtube.com/watch?v=tOdZSSUJ-fI

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5 WAYS TO HELP PARENTS WHO LOST A CHILD DURING PREGNANCY

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How do you help someone who lost a twin during pregnancy? If you’re a friend or family member, it can be difficult to know how to help the family. You’re probably fighting conflicting priorities similar to the parents: Where is the balance between grieving the child who was lost and still finding the joy in the child who survived? How do I express my condolences but still let them know I’m happy about the upcoming birth? What is the right thing to say?

While no two situations are the same, here are some general guidelines that should help friends and family to navigate the emotional needs of parents who lost a twin during pregnancy.

- Listen. This seems obvious, but one of the most helpful things you can do is to be a sympathetic ear. In many cases, the mother will want to rehash the things that went wrong, or which she imagined went wrong, that brought them to that point. Keep in mind that she’s not always looking for advice, but a place to unload her emotional burden.
- Acknowledge their grief. In the face of such daunting adversity, some people think it’s better to say nothing than to say something that would open a raw wound. The opposite is true, actually. Silence can alienate the parents and make them feel as though they are grieving alone. There is a foolproof way to show you care without making anyone uncomfortable: “I’m sorry for your loss.”
- Take cues from the parents about whether or not they want to discuss the baby who passed away. Some will want—need—to talk about their deceased child on an almost constant basis. Others, however, prefer to focus on the surviving child alone, and to keep their grief away from the eyes of loved ones. There is no right or wrong answer, and no two parents will want to handle this situation the same way.
- Don’t forget. The birth of the surviving child is a big day, one that is hopefully full of joy. Make no mistake, however, that the parents are likely feeling the loss of the other baby as though it were fresh again. While it may not be welcome to speak up in the hospital room amidst the balloons and flowers, it is comforting to know that the other baby will never be forgotten. A phone call or a note at a later date is all it takes to remind the parents that both of their children were loved.
- Celebrate! Welcome the surviving baby into the world with open arms and the presence of friends and family who love him or her. Don’t let the sadness overwhelm what should be a wonderful, happy occasion. The birth of a baby is always a reason to celebrate!

Though each mother and father will handle this situation differently, keeping these tips in mind can help you figure out how to help them as they face the loss of one child and the birth of another.

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GRIEF AND BEREAVEMENT: DEVELOPMENTAL STAGES

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Grief is defined as an individual’s response to loss. The way a person responds to loss is unique to each person and is affected by a wide range of influences, such as previous exposure to loss(es), culture, familial grief patterns, the significance of the relationship, and the griever’s age. For many generations it was believed that children did not grieve or, more recently, that their grief was inconsequential. Currently, most people acknowledge that children grieve, but also recognize that children’s grief is very different from that of adults and varies based on the child’s age. More specifically, the expression and impact of grief is closely correlated with the child’s developmental stage.

Developmental stage is a broad concept which attempts to describe how children think at certain ages and how children’s thought processes develop. However, all children develop differently. A given child may be more or less mature in his or her thinking and processing information, than others, at a similar age. There will be some situations in which the child does not “fit” in a certain developmental stage at the anticipated age.

Piaget (1951), Bibace & Walsh (1980), Perrin & Gerrity (1981), Brewster (1982), and others have conducted research that suggests that children’s understanding of loss is closely linked to the child’s developmental stage. Supporting the grieving child, therefore, can be most effective if the child’s developmental stage is considered, as well as the other variables that may affect a specific child’s grief process. Parents, healthcare providers, teachers and other educational professionals, social workers, youth ministers and religious leaders, and all adults who are supporting the grieving child will be better able to address the individual child’s needs if they understand how his/her grief relates to his/her developmental stage.

Families have much work to do after the loss of a child or adult in the family, making it difficult to attend to the complex needs of younger children during this time. For example, if the loss is that of a sibling, the grieving child’s parents may be too consumed by their own grief to be able to actively work with the grieving child on her grief. Or, if the child’s mother dies, this leaves behind a devastated husband and father who now must care for children in the midst of his own, disabling grief.

Many children experience a loved one’s death with no prior experience with loss nor an understanding of what one is supposed to feel and how one is supposed to act while grieving. Some children ease in to grief by first losing a distant relative, a pet, or a family friend who they do not know very well. However, if the child’s first grief experience is the loss of a mother, a father, a brother or a sister, the process is likely to present challenges for the child, as well as for the adults caring for him. Very young children may not have expressive or receptive language skills that enable them to talk about how they are feeling. Although older children may be able to articulate their concerns, they may be embarrassed or uncomfortable sharing such personal feelings with others, especially adults.

Children’s grief does not look, outwardly, like the grief of an adult. Often, children do not have the emotional maturity to grieve for an extended period of time. Instead, children may grieve in “chunks,” being inconsolable one minute and quickly turning off their tears to run outside and play. Although this is sometimes disconcerting to adults, it is a typical way for youngsters to cope with the intensity of their feelings of sadness by returning to the work of the child—playing. Grief may also be expressed by children and adolescents through their behaviors. Regression, declining grades, oppositional behaviors and changes in eating and sleeping patterns are common manifestations of children’s grief.
A unique challenge to childhood grief is the fact that it not only affects children at the time of the incident but also returns to impact children differently at each developmental stage or during various circumstances or milestones. As a result, youngsters must revisit their grief as they move into different developmental stages. For example, the 15-year-old girl who lost her mother when she was 3 years old will grieve anew when she recognizes the intensity of being a 15-year-old who needs advice that only a mother can give. Re-experiencing grief at each new developmental stage is like repeatedly knocking the scab off of a healing wound. It requires expenditure of emotional energy on the part of the child, as well as the adults in his support system, to revisit and work through grief as the child matures. For some adults, it may be confusing to observe the child grieving anew at a time when the adult thought that the young person was “finished grieving.” In reality, the adolescent is moving through her grief. Moving through the grief is different from moving around the grief; the former is required in order to continue moving forward through the grieving process, while the latter can lead to unresolved issues that may become evident later. Further, no one ever completes grief. It is present throughout the griever’s life with the goal being acceptance of the death and the ability of the griever to live in the absence of crippling sadness. With adult guidance and support, healing occurs at each “reopening” of the child’s loss. Hope and healing are most likely to occur when the grieving child and a caring adult work through their grief together. That may be difficult, as both the grieving child and the grieving adult may try to protect one another from further burdens by hiding their emotions. Ideally, the child and adult will experience and work through their grief together, with the goal of emerging on the other side with new skills and understanding about themselves and each other. In addition, the way a parent grieves influences how their child will grieve. There is a reason this process is called grief work, as children, parents, and other caring adults learn soon after the loss.

The following information is provided in the hope that it will provide the adults caring for a grieving child with a better understanding of the cognitive abilities and the developmental status of various ages and stages of childhood and how those impact the experience of grief. However, many factors affect how children perceive death and how they grieve. These recommendations are intended to provide a general framework in which to understand children’s response to death and loss.

**Infants and Toddlers**

Infants and young toddlers, up to the age of 3 years, do not yet have a concept that the world exists beyond them and their caregivers. They are beginning to form strong attachments and, in the first year, will identify the caregivers whom they prefer, usually the mother, father, siblings, grandparents, and perhaps a daycare provider. If a death of one of those key adult figures occurs, the young child will notice the absence and likely feel some degree of abandonment. However, the child has no concept, at this age, of death. He will be able to sense changes in other key adults and will perceive emotional distress in these adults. The adults’ emotional distress may cause the baby to be fussy or to change sleep or eating patterns. The baby or toddler may be observed seeking the person who has died. If she has any language, she may call out for the person and be sad when she cannot find them. Toddlers may evidence some regression such as wanting a pacifier or bottle again and becoming very “clingy” to the remaining caregiver. Separation anxiety may develop with the child being fearful of the remaining parent leaving them at daycare or grandparents’ home. It is likely, however, that the child at this age will adjust and that they will resume previous behaviors fairly quickly.

Supporting the child at this stage consists of providing love and support, rather than more formal grief work. Snuggling and physical closeness will comfort the very young child. He will enjoy favorite routines, familiar songs and hearing the voices of those with whom he feels an attachment. Bedtime rituals, such as reading a story or rocking on an adult’s lap, should be continued without interruption. This provides the child with a sense of familiarity and predictability that has been threatened by the death of a caregiver. At this age, full attendance at the funeral or memorial service is not recommended, but the child could be present for a brief part of the religious rituals or other activities in order to later feel a connection to saying goodbye to their loved one. In addition, pictures of the deceased may be helpful at a future developmental stage in helping the child make sense of what happened. The toddler may ask questions, and he should receive honest answers such as “Daddy is dead, and he will not be able to come back.” Observing dead
insects may also be helpful as the child can begin to appreciate what “dead” means (“You see, the bug does not move anymore. He cannot walk or fly and he does not eat anymore”). Starting at this early age, adults can help the child by modeling expressions of feelings and helping the child name her feelings. It is believed that children younger than 3 years of age do not retain memories. Thus, a scrapbook or memory box with pictures and mementoes of the loved one can be kept for when the child is older and has more specific questions about their loved one who died. If the death is from an illness, perhaps the dying person can write letters or take pictures with the baby, illustrating the importance of the relationship.

Preschoolers and Kindergartners
Youngsters from age 3-years to 6-years are egocentric and believe that the world revolves around them. They are in a stage of development where they can focus only on one thing at a time. The concept of death does not yet make sense to them as they believe that inanimate objects can be alive and also believe that if something “gets dead,” it can recover and “get alive” again later. If Daddy has died, the child may repeatedly ask when Daddy is coming home, if he flew to heaven in an airplane, or where he is sleeping while he is dead. Rather than feeling a great deal of sadness about the person's death, these children tend to react more to the sadness and changes in adults’ behavior around them. Adults may feel confused as they wonder why the child is not sad that his parent just died, but the child is just waiting for his parent to return home. Early stages of bereavement and the behavior of adults may be very confusing and concerning for the 3-6-year-old child. This is the age when “magical thinking” becomes evident. The youngster should be assured that she did not cause her daddy's death. For example, if a child has been put in time-out by Daddy for running and yelling indoors, she may think that her behavior caused her father's death.

The preschooler/kindergartner’s behavior communicates a great deal more than his words. At this age, the child does not yet have a vocabulary or experiences that enable him to express his feelings verbally. Children at this stage of development communicate mostly with their behavior/play. After the death of a loved one, the child knows that he feels different and that the feelings are not good, but he does not know how to express this or to behave. As a result, his behavior may reflect these negative feelings. He may express his feelings in his play and may become engaged in themes of death. Regression, acting out, tantrums, clinging and demanding behavior, overly energetic behavior, withdrawal, being silly at times when silliness may not be expected, and/or a child who is “not herself” are all normal behaviors at this stage. Irritability is common, and he may become concerned with who will take care of him if something happens to the other parent or with whom he will play if his sister dies, too. Going to sleep may induce new fears as he draws parallels between sleep and death. Great care should be used to ensure that death is not explained or referred to as being "just like going to sleep."

The child may raise questions, repeatedly, about the loved one and about the death. At this age, there may be intense curiosity about death as the child attempts to learn something that she does not fully understand. Honest, brief answers in clear, understandable language will usually provide the information the child is seeking. Resisting the urge to tell the child more than she asked will enable her to process the information she was seeking and then be ready to come back for more. Again at this age, attending part of the funeral or service or other religious observance may suffice, for a time. The youngster will also benefit from maintaining as much of a routine schedule as possible, engaging in routines and rituals which are familiar and comforting. Adults may not be focused on the need for the child to have play opportunities, but the child will be focused on that. Allowing the child to play at a friend’s house or ensuring that play time is preserved at home will be helpful.

At the upward limits of this age group, children are likely to retain memories of their loved ones. Making memories such as hand prints of the father may create treasures for the youngster. Photos and memorabilia may strengthen the child’s memories and may be helpful if the child would like more information at an older age. If adults model appropriate expressions of sadness, frustration, and even anger, during the days and weeks after the death, children will learn appropriate expression related to grief and loss.
School Age Children

During the ages of 6 to 11 years, children become very curious about death, injuries, illnesses, and physical manifestations of each. It is around this age that children enter what Piaget (1954) described as the Concrete Operational Stage where they begin to think in a more rational and organized manner and begin to draw on past experiences. As children begin to use logical thought, they are literal and only able to apply logic to physical objects.

Children in this developmental stage have a growing understanding that death is permanent. In addition to the understanding that death is irreversible, school age children are also learning that it is universal and inevitable; in other words, they now realize that all living things die. However, children in this age group are not “little adults” and do not yet have the understanding that adults have about death. The school-age child is very literal and curious about the details of death and related topics. Children in this stage may ask many questions as they attempt to add an understanding of the abstract nature of death to their developing understanding of the logical, concrete nature of death. This may result in discomfort for the adults in his world, who are not accustomed to or don’t want to talk about those topics.

Grief in this stage is affected by the child’s uncertainties about death, their curiosity about what happens at death and after, fear of the unknown or loss of control, and separation from family and friends. School-age is a developmental period when it is common for grieving children to worry, have fears and anxieties. This may lead to the youngster being terrified that their other parent will die and leave them orphaned. Or, they may fear their own death because of their uncertainty of what happens to a person and their body after death. The school age child’s fear of death may be fueled by personifications of death such as the grim reaper, a skeleton, a ghost or even an angel. Helping the child understand what happens at death will enable them to understand that the person is not “taken” by one of these frightening figures. Clear language in describing death will also support the child’s developing understanding. Saying that a parent was “taken to heaven” or that “God takes only the best” may cause additional concerns for the child.

The manner of expression of grief at this stage may be confusing for adults as the child may be crying and consumed with grief one moment and then go off to play with other children. Disruptive or acting out behaviors may occur where they never have before, or the child may become withdrawn and refuse to speak to anyone. These behaviors are to be expected. Children in this stage need supportive adults who can allow the child to ask questions and to openly grieve in their presence. Protecting the surviving parent may be a primary objective of the child as he tries not to show his grief in order to not add to the parent’s sadness. Or, the surviving parent may be so overwrought with her own grief that she is unable to address the grief of her child. In this circumstance, another trusted, caring adult should step in to provide temporary support to the child. In time, the parent and child can, hopefully, support one another as they share their common grief.

Teachers and other school personnel should watch for changes in the child’s school performance. At the first sign that grades are dropping, the school team should intervene to determine how to support the child at school. Social workers, school psychologists, the principal, or a teacher may be the child’s “go to” person during the school day when the child feels overwhelmed by his grief.

When caring adults at school, home, and in other groups in which the child is involved are aware of the needs of a grieving child, supports can be initiated that will enable her to move forward in her grief. It is important to remember that most children do not understand grief nor their feelings when they are grieving. Grief is an unfamiliar and uncomfortable experience for most children and, although they recognize their feelings as negative ones, they are unable to define them specifically as sadness, anger, or anything else they have previously felt. Children must learn how to grieve, and they will be observing the adults in their world as they determine how to do it.

Adolescents

From age 11 to 15 years, the youngster is in the formal operational stage which is characterized by the developing capacity to understand abstraction (Inhelder & Piaget, 1958). With this ability, adolescents can
begin to manipulate concepts, rather than using concrete objects, to understand. Now, the youngster begins to imagine the world of possibilities and to respond logically to symbols and information that may not be in the real world.

By adolescence, most young people have an understanding that death is permanent, that it happens to everyone and that it will eventually happen to them. As adolescents become more able to think abstractly like adults, additional challenging questions arise. Adolescents question the meaning of life, the purpose of the individual in the world, what happens to the physical body and the soul of the person who died, and so on. These questions can be impacted by their family’s culture and religious beliefs. In addition to the challenges that these thoughts bring, this may also be a period of psychological and spiritual growth for the teen.

As with school age children, adolescents will draw upon past experiences and their cognitive and emotional development as they react to the death of a loved one. It is more likely that an adolescent has had some exposure to death, whether it is the death of a loved one, the death of a pet, or hearing about the death of someone famous. However, even if the teenager has experienced grief before, it continues to be a challenging task for most adolescents. During a developmental period that is filled with discovery but also fraught with crisis, the addition of grief may tax the young person’s resources and add strain to an already difficult period of development.

For teens, grief may be further complicated by the reality that they are working toward independence and seeking new support systems as they pull away from their family. As a result, the support system for a grieving adolescent may not be strong, or may be non-existent. Some teens will regress and return to their family for support, thus requiring them to work to distance themselves from family again in the future. Some adolescents will seek a teacher, coach, spiritual leader, or other adult who can provide support for them as they grieve. However, some teens will try to handle their own grief or to get support from a peer who may or may not be able to help. In addition, adolescence is a time when most teens strive to be like their peers, and grief can make them feel “different” from their peer group. Thus, a grieving teen may work very hard to hide their grief, never truly being able to move forward.

There are interesting similarities between adolescents and children in younger developmental stages. Like toddlers and preschoolers, adolescents like to protect routines during times of grief. They may take comfort in reading before bed or spending time in their deceased parent’s easy chair, where they remember him sitting during past conversations. Teens, and many adults for that matter, also engage in magical thinking: Did I cause his crash because we had fought the day before? Or Did I cause Mom’s cancer from all of the times I caused her to worry when I didn’t turn in my homework?

Like school-age children, teens are more likely to express their grief with behaviors than with words. Although they possess the verbal skills to express grief with words, teens may be uncomfortable sharing the raw, confusing emotions that they feel. The behaviors that teens engage in when grieving may cause them difficulties. Some teens may engage in impulsive acting out behaviors that cause them difficulty at school or in other settings. Other youngsters become withdrawn and may experience depression and/or anxiety associated with their grief. For other teens, a decline in grades may be the first sign that the youngster needs help with expressing her grief. Many adolescents have difficulty asking for help or even recognizing that they need help. For this reason, caring adults in the grieving teen’s environment should be especially cognizant of watching for signs of distress.

Commonalities of Grief

Although these developmental stages provide a guide by which to understand children and how they grieve based on their age, it is important to remember that a given development stage may not be manifested at a specific chronological age, and that a child’s response may not always be expected to fit neatly into a specific category. At any age or stage of development, a child may exhibit shock, denial, and anger before they can move forward in their grief. It is painful for children and adults to address grief. Grief “work” is just that, and in order to heal one must walk, head on, through the grief rather than attempting to avoid it or walk around it. Shock, denial, and anger are normal and these difficult feelings
must emerge before youngsters can begin to make sense of their loss and, finally, find the “new normal” in their world.

The challenge in childhood, however, is that children are likely to recognize their loss in new and painful ways as they mature. Grief is cyclical and is sometimes described as coming in waves. Children and adults alike may experience a period of acceptance related to the loss of their loved one, only to be surprised by a return of feelings of hopelessness and helplessness. Those experiences often become less frequent and less painful as time goes on, unless triggered by an inciting incident or milestone.

Children, for the most part, are resilient and can be successful in making adaptations in their world—as long as they are surrounded by caring adults who are willing to work with them. Parents, grandparents, aunts, uncles, friends, teachers, coaches, clergy, activity leaders, and others should be available for the grieving child, without telling her how she “should” grieve and without bringing up the child’s grief.

Allowing the youngster to be in control of when, and to whom, he will talk about his grief is often the best plan. Allowing room to express grief through behaviors to the extent that is appropriate, being present for the child, acknowledging the child’s grief, letting the child play, allowing the adolescent to be with friends and letting the youngster know they are loved and cared about will provide a strong foundation for the child to successfully engage in his grief work.

**If the Child Needs Additional Help**

At some point, every human being experiences the loss of a loved one. Grief is the normal experience that follows such a loss. Most children and adults are able to move through grief and loss. Only under extenuating circumstances will a child need to seek professional counseling for his grief. Professional counseling may be needed, for example, if the child's behavior is out of control, if the surviving parent or other caregiver is unable to help the child through her grief or, if despite time and support for the child he still seems to be experiencing grief that is not lessening over time. Parents may ask the child’s pediatrician, his or her school counselor, or the person who leads their place of worship if they have recommendations for counseling. Some communities have grief centers for children that may be helpful and school social workers or counselors may conduct grief groups for students. Even though the grieving process is a personal one, children and adolescents may take comfort in just knowing they are not the only one who has suffered a loss. The hospice who provided care for the patient may offer bereavement support to the child and other family members. Social workers and psychologists may offer individual and group counseling.

There are several sources of written material including the local library, the child’s school, and even the Internet. Those working with the child should ask for recommended resources, making sure that the source is a credible one.

In recent years, hospices around the country have started offering a wide range of family and individual grief experiences including groups that meet weekly, day camps, and residential camps. The professionals who provide these services usually have additional training in grief and bereavement support.

Above all else, each child is a unique individual who will process grief in their unique and individual way. Children need a grief guide who will be there to listen, to help them express what they are feeling, and to address their needs. Active listening is imperative, where the adult does not judge nor tell the child how to grieve. Rather, the adult allows the child to say, draw, write, or otherwise express whatever she is thinking and feeling. In addition, when possible, the adult should demonstrate through their behavior a way of working through grief. The adult should be respectful and supportive, regardless of how old—or young—the child is. Adults often report that they learn a great deal from a grieving child—not only about the child, but also about themselves.
References


Resources for Parents, Teachers and Other Caring Adults

- The Dougty Center, The National Center for Grieving Children & Families http://www.dougy.org/
- NCTSN – the National Child Traumatic Stress Network http://www.nctsnet.org/resources
- American Cancer Society, Children and Cancer http://www.cancer.org/treatment/childrenandcancer/index
- Sesame Street http://www.sesamestreet.org/parents/topicsandactivities/toolkits/tlc/griefresources
- National Alliance for Grieving Children https://childrengrieve.org/
- Coalition to Support Grieving Students http://grievingstudents.scholastic.com/
- Willow House Grief Resources http://www.willowhouse.org/grief-resources.html

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RITUAL IN PERINATAL BEREAVEMENT

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Setting the Stage

The term “bereavement” may carry with it multiple meanings to any individual, but typically includes feelings of loss and sadness (grief) and an existential experience of suffering. According to Fenstermacher and Hubcy (2013), “perinatal bereavement is a multi-faceted global phenomenon that follows perinatal loss” (p. 2389). When a child dies, parents frequently report an intense longing for their child, oftentimes described as pain in one’s chest from a broken heart. Mothers of infants may experience aching in their arms, a physical longing to hold the baby who died. Uncontrollable crying may alternate with feeling numb and emotionless. Even laughter can resonate through a room where a child is dying or has just died.

Stroebe and Schut (2010) called this process “oscillation” (p. 273), a dynamic back-and-forth between restoration-oriented coping (stoicism, courageous confrontation) and loss-oriented coping (allowing for expression of sadness and despair). Parents may describe this as a roller coaster of emotions, which can be a helpful metaphor to use in describing what they may experience for a long time, perhaps indefinitely. Understanding what to expect as time passes can help parents anticipate and prepare for what their lives may offer them as the hours, days, and weeks since their child’s death pass by.

Evidence-Based Background

Current bereavement research underscores the importance of legacy creation (Ives-Baine, 2010), which includes keepsakes, photos, hand- and foot-prints and molds, and other tangible items. These mementos serve as touchstones for parents, siblings, and other loved ones as they adapt to the “empty space” (McGlowry, Davies, Kulenkamp, May, & Martinson, 1987) the child’s death leaves within the family. Cacciatore and Flint (2012) identified the role of ritual as a way of continuing the emotional bond with the deceased, establishing a sense of control at a time when emotions seem uncontrollable, and providing opportunity for personal growth and transformation as part of the traumatic experience of death.

Two points these scholars make are particularly relevant to this discussion: The participants involved in the study sought a more private expression of ritual in the immediate time after the death (the first few months) and embraced more public expressions as time progressed. Ritual in a public setting may mean participating in a remembrance walk, memorial service, or another opportunity to join with other parents to create a ritual.

Meaningful Moments and Ritual

Creating memories that live in one’s heart and mind are ways to find comfort after a child dies. Ritual is a way of making the most of moments that matter (Limbo & Kobler, 2015). According to Rando (1986), ritual is a “specific behavior or activity that gives symbolic expression to certain feelings and thoughts” (p. 402). The beauty of ritual when used in grief and bereavement is the ability of all who participated to bring the actions surrounding the ritual to mind, anytime. In our book, Meaningful Moments: Ritual and Reflection When a Child Dies, Kathie Kobler and I describe numerous rituals that parents and caregivers have shared. Each centers on a meaningful moment, one that those involved will not forget.
The book begins with a story about Eliot, who lived for 99 days with Trisomy 18. Each day became a ritual as his parents and those nearby celebrated his birthday at the exact time he was born. Imagine the memories that wash over all those who honored Eliot’s short life in such a meaningful way. Like many rituals that occur within a healthcare setting, this one was co-created, a term Kathie and I used (Limbo & Kobler, 2013) to illustrate the joint connection between parent and care provider that leads to the symbolic creation of something lasting. Eliot’s father, Matt Mooney, described the co-creation of Eliot’s birthday ritual in this way:

We were discussing to ourselves how the clock was creeping toward 4:59pm, and he had been with us for 24 hours, his first unpromised day. Moments later, one of the nurses quietly came alongside us with what she called a “birthday hat,” a small circle of tinsel she had heisted from a bulletin board celebrating the 4th of July. She proceeded to hand the sleep-deprived new parents a piece of “birthday cake,” otherwise known as breath mints, for Eliot’s party. We laughed at her ingenuity as all who were present gathered around to sing happy birthday in hushed tones; such a familiar song rang out in such an unfamiliar setting. (Limbo & Kobler, 2013, viii).

Ideas of Ritual from Bereaved Parents

Miscarriage occurs in 15–20 percent of known pregnancies. Yet, often there is no baby to see, no photos to take, no family gathered to stand vigil. For the families for whom the miscarriage represents “baby,” “child,” and “family member,” having no tangible remembrances can make their heartache deeper. Creating their own keepsakes can be a form of ritual. The photo shows what one couple calls an “altar” they put together in memory of their baby who was miscarried in early pregnancy. Note the numerous small items, safely tucked into the jar.*

When a baby dies so early in pregnancy, parents and others close to the baby may not consider at the time the pregnancy ends that rituals are even possible. Therefore, a health care provider might suggest a ritual to be done years in the future, when family members may be comforted by such a commemorative act. A loss through miscarriage may also be commemorated through burying items the parents had hoped to use with or for the baby (e.g., a blanket, toy) even though the baby was not buried. Other ideas that may become a ritual include

- Wearing a baby ring on a chain around one’s neck
- Choosing a name for the baby
- Engraving the name on a rock in the garden
- Planting a tree or other vegetation in a place one sees each day

The following are other rituals that parents, either in collaboration with staff or on their own, created to honor a special time and special relationship for an older baby or child:

- Reading a book to the child, one that has meaning to other children, or to the dying child—the book may also be one that parents had dreamed of reading to their baby, perhaps one that had meaning in their own childhoods
- Naming a baby born many years before and engraving the name on the cemetery headstone
- Placing items of clothing, blankets, toys, books, or poems written for the child in the child’s casket
- Encouraging bereaved adults and children to use the casket as a writing space where they can draw pictures, write notes, and use colors that have meaning within the family (e.g., a sports team)
- Planning and getting a tattoo
Ritual for Care Providers

The death of a patient can provoke intense suffering for those who have been the child’s care provider, whether in the hospital, home, or outpatient setting. Ritual is one example of a way that staff members from all disciplines can come together to establish a connection with each other and honor the patient who died and the family. The ritual can be simple: gathering those who are available to step inside the child’s room after he or she is gone, standing in a circle—perhaps holding hands—and, either silently or with a few words, blessing the space prior to the admission of another patient.

Some bereavement coordinators have special materials available that can be taken from a cabinet when they are needed so that staff members can develop a special ritual appropriate to the moment. The materials may include a hope chest (into which written words of sadness, comfort, or suffering can be placed as each person arrives or leaves for a shift); beads in many colors, with a color-coded guide to the meaning of each color posted near the beads; feathers; or a small wooden box filled with sand.

The sand ritual can be quite powerful: as staff members place one hand into the sand, watching as everyone takes turns leaving their own print. This symbol of team, the important work of one’s hands in caring for those who are dying or their loved ones, the shifting sand as representative of the changes in grief and suffering—these meanings and more may be taken away from the sand ritual. It is important to allow personal meaning to frame ritual, allowing each person who takes part to come away with their own meaning of the moment.

Logan’s Story: Photography to Capture Family and Care Provider Ritual

Bereavement photographer Todd Hochberg (n.d.) has captured many meaningful moments of ritual while photographing families and their care providers around the time of death. One photo, which is included in our book (Limbo & Kobler, 2013, p. 24), shows the spontaneous moment when the staff said goodbye to Logan and his parents. With his mother holding Logan and his father’s hand on his head, the staff formed two circles, placing their hands on Logan in a goodbye blessing. The chaplain who was present spoke a few words while everyone present participated in this extraordinary moment in time, showing the circle of love surrounding Logan and his parents, a memory to be kept in their hearts and, through a photograph, a keepsake to be treasured for the rest of their lives. I recently spoke with a nurse who was present when Logan died. When she saw the photo in our book, she said, “I was in the outer circle.” I sensed that sharing those few words with me took her back to the time with Logan and the recognition of his gift to her.

Ritual often inspires poetry. Kathie Kobler’s poem in memory of Logan, written when she awoke at 2 o’clock in the morning thinking of him, contains these stanzas:

Before we met, I was stuck in my own agenda, concerned for time, watchful of the hours.  
Because of You, Little One, I was struck by the power of a moment and humbly wondered how your soul slipped from the constraints of our man-made time into eternity;  
Before we met, I was weary. Because of You, Little One, the weariness remains joined by a sacred peace. (Limbo & Kobler, 2013, p. 41).

The excerpt from Kathie’s poem demonstrates the powerful effect of relationship on care providers, knowing that they have made a difference, and honoring a connection for which there is no end.

Ritual flows from relationship  
Relationship forms a bridge from suffering to hope  
Hope transforms.  
(Limbo & Kobler, 2013, p. 79)*

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Resources

- **www.Aftertalk.com** (Website for private grieving rituals, inspiration, ask the expert column by Dr. Robert Neimeyer)
- **www.advancingexpertcare/hpcc** (Hospice and Palliative Credentialing Center: Certified in Perinatal Loss Care and Pediatric Palliative Care exams)
- **www.perinatalhospice.org** (Resources for parents and professionals; literature; list of programs)
- **www.gundersenhealth.org/resolve-through-sharing** (Education for professionals [perinatal; neonatal/pediatrics; pediatrics/adult]; written materials and keepsakes for parents and professionals)

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ART THERAPY WITH BEREAVED CHILDREN

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A child in grief may have a similar experience to an adult, in that the intensely powerful feelings associated with the death of a loved one leads to physical and psychological symptoms that can be distressing. How a child grieves can vary depending on many factors including developmental understanding of death, previous exposure to death, and the support and environment surrounding the child. Often, a child may not be adept at expressing his or her feelings through words alone. Art therapy is a modality which allows for children to receive counseling surrounding their grief, encourages sharing of feelings, and promotes effective coping strategies to manage grief.

This therapist is part of the Pediatric Advanced Care Team at The Children's Hospital of Philadelphia, working on this multidisciplinary consult service since 2004, providing palliative care support to patients, siblings, and families in the hospital and home based setting. Generally, the team is consulted during a patient's admission and then follows thereafter, based on needs and goals of care. After a patient's death, brothers and sisters [or close family members 'like' a sibling] can still receive bereavement support from psychosocial team members which often takes place in the family's home.

Since every child will experience his or her grief in his or her own unique manner, the art therapy process as well as a child's participation will also be individualized. Meeting children at their level, developing the therapeutic relationship, learning about their needs, and discussing their wishes for their time aids in shaping the activities and plans for sessions. Many options, ideas, and choices are offered by the therapist; guidance and attention encourages verbal dialogue during the home visits. Sessions occur 1:1, with a small group of children or as a family.

There is not an abundance of research giving measurable data on why utilizing a particular modality is helpful, yet being allowed into families' personal lives to assist with the grieving process, more examples than can fit into this paper, have been experienced. Here is just one to outline art therapy:

J, was a 5-year-old sister to 18-month V, who had a metabolic stroke during hospitalization and would not survive the admission. After participating in some memory making as a family with the inpatient child life specialist, J met 1:1 with the art therapist and continued with legacy activities. In this initial session, the two main goals were to foster the therapeutic relationship and to provide an outlet for J to express her feelings related to the impending death of her sister. Creating a memory/treasure box to keep special items that were about her sister or that made her think of her sister, J was able put a lot of time and energy into finding stickers and using up all the space both inside and outside of the box. She was verbal with the therapist throughout—sharing about herself, her sister, and her family while creating the box. Of special note was the excitement in her voice when she found matching stickers, both a big [herself] and small [her sister] princesses—which she placed on the top of the treasure box and announced it was the two of them. Also of note in this session, she did not fully grasp the concept of death, as evident by her comments when she spoke of conflicting ideas. She mentioned that her mom and dad said "V is not going to get better; she is not going to come home with us; she is going to be up in the sky," yet J also said in conversation "When V gets bigger, she is not going to be sick anymore." This sort of magical thinking is not uncommon at 5 years of age, with death being such an intangible concept to understand. Parents and caregivers often need to reiterate the finality of death to children. Children will need to ask questions and hear the information repeated. Participating in follow-up counseling can support this need; having someone outside the family who is able to assist with going over such concepts can be helpful to family members who are grieving themselves.

J's sister died that evening surrounded by the family. Mom kept in communication with the therapist during the time up to the funeral and shared that J wanted to have her sister be buried with the treasure
box. Her parents were going to honor this wish. Together, the family decided that the treasure box created at the hospital, as well as one of the ink hand and foot prints were placed in the casket next to V. Additionally, J drew a family picture and chose a stuffed animal that she had received as a Christmas gift to accompany her sister. In exchange, parents gave J a bear that had been given to V and mom reported that J had grown extremely attached to it. She would carry it around, calling it “V bear” or “Princess bear”—she would even put it in her sister’s high chair at the dinner table and slept with it at night.

After the funeral services, the parents called the therapist and emailed a picture they wanted to show our team. It was drawn on a magnadoodle toy by J after coming home. J expressed to her parents that it was a picture of when they saw V in the casket and gave her the gifts with which she would be buried. Despite the sadness of the event, everyone is smiling in the picture, as they place things in the casket. All the females in the picture are depicted with crowns, aligning them together. When parents raise questions about including siblings in the funeral process and rituals, especially younger ones, it is important to remember that a child’s imagination of what occurs at a funeral or what their brother or sister looks like can be worse than actually participating, seeing for themselves, and being allowed to say goodbye. Religious beliefs and customs can also be explained to children in a manner that they can comprehend and at their developmental level—again, the unknown is almost always worse than the reality. A child’s participation in such rituals tends to promote more good than harm to surviving children.

J continued to participate actively in home visits for several months after V’s death. Activities included a combination of legacy tasks—a new treasure box was created about her sister—as well as developmental tasks to allow her to focus on herself and explore navigating a new “normal” in the family’s life. She seemed to be coping well, speaking freely about her sister with her family and also allowing the time and space to continue to grow and think about herself. She looked forward to art therapy sessions as evidenced by the artwork she created for the therapist in anticipation of the visit and then presented at the onset of each home visit. She had a lot to say, would create detailed drawings, and then tell elaborate stories to describe the artwork. She would then have therapist write down the narrative for each piece. Themes often included happy feelings, families together, safety of those that are alive, and comfort/company for those who had died. She was able to depict the new make-up of her family and she regularly drew her sister and a grandmother at the top of drawings. She talked about her sister as watching over them [her family]. She would frequently state ideas about V being happy “as she watches us, our family here.” Many tasks also centered around family photographs, with J looking through them with her parents before a home visit and then using them during art therapy to create collages and frames for the photos.

The therapist and parents planned for and utilized a transition in J’s life to end the home visits. She had begun kindergarten in the fall and we were able to have this coincide with winding down her participation in art therapy. The parents were able to continue supporting J as she readily utilized creative outlets to express herself through art making and sharing.

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THERAPEUTIC BEREAVEMENT INTERVENTIONS FOR TEENS: BEREAVEMENT GROUPS AND CAMP

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Adolescence is generally a time of great turmoil for the teen, as well as his/her parents or parental figures. My extensive experience working with young bereaved parents and grandparents raising their children's children, has given me an appreciation of the special needs of bereaved teens.

Developmentally, one of the principal tasks of adolescence as they transition into adulthood is parental independence, as teens struggle to determine their own personal identity (Corr & Corr, 7th ed., 2010). For teens, the struggle to grieve a significant loss (whether parent, sibling, other family members, or friends) often complicates this need for separation as they may be pulled back into the family unit. An example that easily comes to mind are frequent comments telling a daughter “you're now the mother of the family” carrying the expectation that the teen will now assume the care for younger siblings, perhaps also taking over daily chores, e.g., cooking and cleaning. Adolescent boys are frequently told (or instinctually believe): “You're the man of the family now and have to work now to help support the family now that your dad is not here.” After a significant death the teens may be drawn back into their family unit which may create feelings of resentment and bitterness which can contribute to feelings of guilt (Jeffreys, 2011).

It is well documented that how children and teens cope with a significant death is in part dependent on how their surviving parent (or parental figure) is coping (Christ & Christ, 2006; Sandler et al., 2003; Wolchik et al., 2006; Worden, 2014). Good parenting skills are beneficial in helping bereaved teens. Given space constraints, this article will not discuss the number of bereaved teens, statistics on the various losses they incur, or the specific factors that influence their grief (e.g. religious, socioeconomic, cultural, social supports). Instead, I will focus on identifying specific therapeutic interventions for bereaved teens, which have been developed by Calvary Hospital (Bronx, New York). For the past 20 years, Calvary has provided services for bereaved children and teens. Each year as our program expands we add new activities to meet the needs of grieving teens in therapeutic ways congruent with current research and timely clinical interventions. This article will address the therapeutic services we provide for teens, ages 12-18 years; we will not include our services for younger children (ages 6-11 years) or services we provide for young adults (ages 19-25 years).

The Bronx, one of the five boroughs of New York City, is an urban area and the teens we serve reflect the diversity of New York City. Many of these teens are economically disadvantaged and live in poor, inner-city neighborhoods. More than two-thirds are Latino and African American and in many cases family ties are tenuous. Additionally, Calvary Hospital has approximately 4,000 cancer deaths a year. Since bereavement services and programs are extended to bereaved families in the community, the need to facilitate healthy bereavement, from cancer deaths as well as violent, sudden deaths, is great.

Weekly teen support groups are held all year for adolescents which affords the teen an opportunity to interact with other bereaved peers, helping them realize that they are not alone. The hundreds of teens who have attended and evaluated the groups note that the groups have been helpful as well as enjoyable, where they participated in art therapy and other expressive opportunities as effective methods for facilitating their grief. Referrals for these services come primarily from school clinicians (guidance counselors, social workers, teachers), case managers at Administration for Children’s Services (ACS), or from family members themselves. Face-to-face intakes are conducted prior to the start of group.

We have found that our teens prefer to be in large groups with other teens, rather than the 8 to 10 size groups our younger children and adults prefer. It is not unusual for our teen groups to swell in number to
14 or 15 teens. Various modalities of expressive therapy are included in the sessions including music, dance, different types of art mediums, and the addition of therapy dogs. Therapy dogs were started last year and have been a comfort and a tremendous boost to the teen groups.

Music is an integral part of the group – listening to music, writing music, singing etc. The teens share meaningful music that stirs their bereavement reactions (for example, Dance – Nas; I'll Be Missing You - P. Diddy and Faith Evans; The Message - Dr. Dre and Mary J. Blige; Angel - Sarah McLachlan; Candle in the Wind – Elton John; Dance with my Father – Luther Vandross; Fly – Celine Dion; One Sweet Day – Mariah Carey & Boyz II Men; Tears in Heaven – Eric Clapton; You Pulled Me Through – Jennifer Hudson; Slipped Away – Avril Lavigne; and Concrete Angel – Martina McBride). They have also spent time creating lyrics and music for their own specific losses.

One of the exercises our teens engage in, includes mask making drawing on the concept that we don't always show the world what we are really feeling. The teens decorate masks (bought at craft stores) with marking pens or paint depicting the way they think others view them or the feelings they show to others. On the inside of the mask they are instructed to draw how they actually feel. This exercise encourages the teens to share their feelings but also recognizes those feelings we don’t share with others. Other variations of this exercise could be using boxes and keys which lock our feelings on the inside, and what it might take to use the key to open up with our feelings. One 16-year-old girl drew a question mark on the forehead of her mask and a cross over her mask’s mouth. On the inside of her mask, she just painted the entire mask black. This teen discovered her older brother who had died by suicide (he hung himself). Because of the stigma associated with a suicide, she was instructed by her mother not to tell anyone how he died. Despite a very large family, no one knew how her brother died as they were told he died because “he was sick.”

The teens like making their own “Grief Collage” depicting what their grief is like for them (drawing or cutting out photos from magazines) and discuss appropriate ways to express their grief (e.g., sports, punching pillows, hitting a punching bag; crying). Frequently, the teens will express feeling “safe” in the group because everyone understands their grief. However, others, who have not had a loved one die, do not understand what it is like for them. We do an exercise where the teens trace a shoe on a large piece of construction paper. They write (or draw) what it is like “to walk in my shoes.” Their creativity is remarkable.

Rocks are used in different ways. In one exercise, each teen chooses several rocks: four smooth, polished rocks and one rough rock. The teens use the smooth rocks to describe how they have healed and perhaps even grown since the death and the rough rock symbolizes the hurts that may still exist. Sometimes they decorate the rocks (painting them with colors that are symbolic and hold important memories for them; sometimes using glitter to decorate; sometimes writing words of affirmation on the rocks.

Giving teens “permission” to laugh as well as be sad has been an important aspect of our groups. We provide various opportunities for the teens to have fun including taking them to professional sporting events. We frequently take them to the movies and out for burgers and ice cream afterwards. This gives us the opportunity to process the movie and discuss bereavement implications as the teens frequently relate to the movie shown. Recently we took the teens to see “The Fault in our Stars.”

Camp Compass® was initiated in 1997 when we identified a further need to support bereaved children and teens. This week-long day camp is financially supported by Calvary Hospital and also funded by donations and grants. Camp Compass® occurs during the third week in August, generally a time when summer school is over (many of our teens need to go to summer school) and preparation for next year’s session begins almost immediately after we return from camp. Teens are invited and look forward to attending the camp. They submit the necessary paperwork (medical history, allergies they may have, any medications that they are taking, proof of immunizations, etc.) and guardians complete a consent form allowing for emergency treatment. Last year’s camp hosted 101 kids/teens giving the teens an even greater opportunity to meet and spend time with many teenagers. Over the years we have recognized that our bereaved teens certainly need validation of their concerns, fears, and feelings. Yet, they also
need the special attention of having adults listen to them (really listen to them) as they share their thoughts. For this reason our camp proudly maintains a 2:1 ratio for all our campers. This has been invaluable and therapeutic for our teens, knowing that there is always a counselor available and present. Initially all our counselors were Calvary Hospital staff, however, as our numbers have grown, it has been impossible to use only our staff. In the past three years we have hired counselors that are all professionally trained (school social workers, guidance counselors, mental health counselors, psychologists, etc.) so that we can maintain our 2:1 ratio. Similar to the ending of our group sessions, at the end of Camp Compass® campers, counselors, and parents/guardians are given evaluations to complete.

Camp Compas®s is now entering its 19th season. This unique program benefiting bereaved children and adolescents has proven itself successful to the campers and the families or guardians caring for them. The counselors consistently vie for a position on the Camp staff, and the administration and loyal donors consistently support the program financially. With encouragement and guidance, the program can be replicated in other institutions bringing support to bereaved children throughout our country.

References


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READER’S CORNER

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Two brief useful articles from the Canadian Paediatric Society. The articles are available on the journal website.

Paediatric palliative care in Canada: A national survey of paediatricians. Cyr C, Maisonneuve M.

**Summary:** Beginning with a case study, this brief article and accompanying commentary review the status of pediatric palliative care (PPC) from the viewpoint of pediatricians in Canada. A fair percent (17%) defined PPC as end-of-life care only. Pediatricians noted the need for PPC services but infrequently referred patients. Not all pediatricians accepted the usual triggers for referral to PPC. In some cases, access to PPC services was limited. While most pediatricians identified palliative care needs and services, less than half of respondents felt that their patients were receiving all needed services. Professional needs such as easier access to a PPC team, more PPC education, and additional multidisciplinary support to manage their patients with palliative care needs were mentioned by less than 20% of pediatricians. The authors recommend PPC education opportunities such as palliative medicine, bereavement, decision making concerning limiting no longer beneficial treatments, and spiritual issues.

**Who** is the audience for this information? This is geared toward community PPC providers of all professions. However, as PPC specialists are generally the educators and researchers, they will be interested in this information from our neighbors to the north.

**What** is special about this article? The bottom line is that, even in Canada where pediatric palliative care has been well established for many years, there are still needs for enhanced exposure to PPC during residency and continuing education about the broader aspects of palliative care beyond end of life care.

**Where** and how can I apply this information? This “needs assessment” will be helpful to justify expansion of PPC programs and PPC training in the US.

* * *


**Summary:** The editorial was written by a community pediatrician who practices far from a children’s hospital and who cares for many children with medical complexity. He collaborates by phone and e-mail with subspecialists and a nurse from the adult palliative care service. He notes that the perception that palliative care is end-of-life care is a challenge for parents whose child would benefit from PPC services. Other challenges that he notes are with prognostication, using developmentally appropriate conversations, including the child in decision making, symptom management especially at end of life, and bereavement support for families and providers. The number of PPC physicians is inadequate and these providers are localized primarily in children’s hospitals. This gap is likely to grow as the number of children surviving with chronic conditions increase. He supports evidence-based quality palliative care provided by community providers in collaboration with regional specialty teams and academic mentors.
**Who** is the audience for this information? This is geared toward community PPC providers of all professions and the subspecialty physicians who collaborate with them.

**What** is special about this article? This is primarily a commentary from a pediatrician caring for complicated children in the community. He emphasizes the challenges and suggests some solutions.

**Where** and how can I apply this information? Think about this when talking to families, interacting with PPC professionals, and in planning programs including coordinated care across providers and sites of care.

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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.nhpco.org/pediatrics. Also, more palliative care resources are available at www.nhpco.org/palliativecare, including:
   - Community-Based Palliative Care
   - Legal and Regulatory Resources
   - Webinars and Courses
   - Plus more for NHPCO members

2. Pediatric Hospice and Palliative Care Resources:
   - I-Pad App for Grieving Children. “My Good Grief Journal for Kids” can be downloaded as a tool to help adults talk with a grieving child in a private, secure environment on an iPad. The app provides a child an opportunity to create a lasting journal of memories, thoughts and feelings about their deceased loved one. Visitors to the app are greeted by Gigi, the parrot, who helps guide them through the app pages. The app is a free download at the iTunes App Store. Learn more at http://mygoodgriefjournalforkids.com and read the article.

3. Pediatric Hospice and Palliative Care Training:
   - Hospiscript's Annual Conference, June 23-24, 2016, New Orleans, LA. This two day conference will include a pediatric-specific track, as well as general sessions. More information will be available at www.hospiscript.com soon.
   - NHPCO’s Fall Conference, The Intensives - Mastering What’s Next in Patient and Family Care, October 31-November 2, 2016, Hollywood, FL. Note: The conference will include a pediatric intensive that will focus on community-based pediatric palliative and hospice care. More information will be available soon at www.nhpco.org/conferences.
   - 2nd Annual Pediatric Palliative Care Coalition Conference, October 27, 2016, Pittsburgh, PA. Sarah Friebert, MD, FAAP, FAAHPM (Director of the Haslinger Family Pediatric Care Center at Akron Children’s Hospital) is the featured keynote speaker who will discuss “National Trends in Pediatric Palliative Care.” Visit www.ppcc-pa.org for more information.

4. Journal/News Articles:
   - Nevada's First Outpatient Pediatric Palliative Care Clinic Opens at Children's Specialty Center of Nevada. Families whose children are affected by life-limiting conditions have a new resource to provide better understanding and better outpatient care for their loved ones. The Pediatric Palliative Care Clinic at the Children’s Specialty Center of Nevada is groundbreaking in its efforts to assist parents in this highly specialized medical treatment and is the first such program for outpatients in Nevada. Read more.
   - How one mom's extraordinary love transforms the short lives of hospice babies
     Cori Salchert calls the home she shares with her husband, Mark, a "house of hope." A former perinatal bereavement nurse with eight biological children, Salchert began adopting what she calls "hospice babies" —babies with life-limiting or terminal diagnoses — in 2012. Read more.
   - Pediatric Blood and Cancer A special issue/supplement of Pediatric Blood Cancer focused on the pediatric standards for the psychosocial care of children with cancer. Read more.
   - Falling Together—Empathetic Care for the Dying- The nature of prognostication means we will sometimes be wrong. And the nature of disease means we will often have no cure to offer. But the nature of hope requires a sort of empathy that is not about feeling what our patients feel, but instead about seeing in them what they can be. Sometimes that means refusing to fall, but sometimes it means falling a bit together. Read more.
5. **Subjects and Contributors for Future Issues of this E-journal**  
For upcoming 2016 E-Journal issues, we plan to address issues related to: Communicating with Children, Pain Management, and Symptom Management. 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, like the one in this issue, 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. **Calendar of Events**  
As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, www.nhpco.org/pediatrics. ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics. Please e-mail Christy Torkildson at christytork@gmail.com to have your pediatric palliative care educational offering listed.

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**FINAL NOTES**

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 800-846-6460.

Visit the ChiPPS Web page at www.nhpco.org/pediatrics for previous issues of this E-Journal, additional materials, and other resources of interest.