

# ChiPPS E-Journal

*Children's Project on Palliative/Hospice Services*

*Released in collaboration with the National Hospice and Palliative Care Organization*

National Hospice and Palliative Care Organization  
1731 King Street, Alexandria, Virginia 22314  
[www.NHPCO.org/pediatrics](http://www.NHPCO.org/pediatrics)



**ChiPPS E-Journal**  
**Pediatric Palliative and Hospice Care**  
**Issue #51; May, 2018**

**Issue Topic: Offering Support in Crisis/Traumatic Situations**

Welcome to the 51<sup>st</sup> issue of the ChiPPS E-Journal. This issue of our E-Journal explores topics related to offering support in crisis or traumatic situations. Professionals and volunteers whose primary work involves caring for children, adolescents, and families in pediatric hospice and palliative care programs occasionally find themselves confronted with crisis or traumatic situations in the communities they serve. How can professionals and volunteers best respond to such situations? How can they best prepare themselves to be helpful in these encounters? This issue seeks to provide at least a beginning in discussing these matters.

This E-Journal is produced by ChiPPS (the Children's Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by ChiPPS's E-Journal Workgroup, co-chaired by Christy Torkildson and Ann Fitzsimons. Archived issues of this publication are available at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).

Comments about the activities of ChiPPS, its E-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Our tentative plan for the remainder of 2018 is to develop issues on caring for diverse families/populations, as well as adolescents and young adults. If you have any thoughts about these topics, contributors, or future issues, please contact Christy at [christytork@gmail.com](mailto:christytork@gmail.com) or Ann at [ann@here4u.net](mailto:ann@here4u.net)

***Produced by the ChiPPS E-Journal Work Group***

- Charles A. Corr, PhD, Member, Board of Directors, Suncoast Hospice Institute, Pinellas County, FL; Senior Editor
- Kathy Davis, PhD, MSED, Director, Pediatric Education and Palliative Care, Department of Pediatrics, University of Kansas Medical Center, Kansas City, KS
- Ann Fitzsimons, BS, MBA, Executive Director, here4U, Inc., Farmington Hills, MI; Co-Chair
- Betsy Hawley, MA, Executive Director, Pediatric Palliative Care Coalition, Pittsburgh, PA
- Melissa Hunt, PharmD, Pediatric Clinical Pharmacist, HospiScript, an Optum Company, Montgomery, AL
- Nathan Ionascu, MD, Bioethics Consultant, Westchester End-of-Life Coalition, Westchester County, NY
- Kelly Cronin Komatz, MD, MPH, FAAP, FAAHPM, Clinical Medical Director, Community PedsCare Program, Medical Director, Pain and Palliative Care, Wolfson Children's Hospital and Wolfson Center for the Medically Complex Child at University of Florida, Jacksonville, FL
- Rachel Levi, PhD, Licensed Psychologist, Private Practice, Oakland, CA
- Suzanne Toce, MD, Retired Neonatologist, Gundersen Lutheran Health System, La Crosse, WI
- Christy Torkildson, RN, PHN, PhD, FPCN, Director, UCSF Benioff Children's Hospital Oakland Pain and Palliative Care Program; Co-Chair



**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](http://www.nhpco.org/pediatrics)

## Issue #51: Offering Support in Crisis/Traumatic Situations

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

### Where Do I Start?

p. 5

#### Scott Newport

In this article, our resident poet, essayist, and father of a child who died at a young age, reports on his participation in a training session for parent and professional teams. The young doctor who was Scott's teammate was challenged by having to interact with a middle-aged woman who had a severe speech impediment that left her struggling to form the words that her mind wanted to convey. Scott reflects on the kindness shown by this young doctor in helping to fill in the blanks in her conversation with the woman and he links this to his hope that he “can be a person who opens a window for families when they suddenly find themselves feeling suffocated by the diagnosis of having a child with a complex medical condition.” What do we do when we encounter unexpected, even crisis, situations?

### Double the Pain: Hope Unlimited

p. 7

#### Marisel Nasis-Matuza, MS, RN, CPNP

The author relates the experiences of a couple who encountered severe health challenges that afflicted their first child and caused his death before his first birthday. They only learned why this happened after their third child was diagnosed with Alpers syndrome (Mitochondrial DNA depletion syndrome-4A) before he, too, died. Interviews with the mother describe how difficult it was to face these incurable illnesses in two of their children and report efforts to create a foundation to raise money for research in this field.

### When a Child Dies in the Emergency Department

p. 13

#### Suzanne S. Toce, MD, FAAP

Dr. Toce advocates in this article for the value of applying palliative care principles when a child or adolescent dies in an emergency department. She shows how these principles can guide care of the child, care of the family and others involved, care after the child dies, and staff support. A list of Resources completes this article.

### More than Grief: Supporting Traumatized Youth after a Crisis

p. 19

#### Judith A. Cohen, M.D.

After noting the widespread prevalence of traumas affecting children and adolescents, Dr. Cohen provides clinical examples and a detailed table to assist in recognizing five clusters of child and adolescent trauma symptoms. She sets forth promising ways of responding to child and youth trauma symptoms, both during the first month after the crisis and later on.

### Cultivating Resilience

p. 24

#### Kathy Davis, PhD, MEd

While noting limitations in our current understanding of the concept of “resilience,” Dr. Davis argues that efforts to cultivate resilience can be especially helpful in enabling children with serious illness and their families achieve their full potential. In order to help such children and families, she then provides guidelines grouped in four broad strategic categories that parents and health care providers can use: facilitating supportive adult-child relationships; building a sense of self-efficacy and perceived control; providing opportunities to strengthen adaptive skills and self-regulatory capacities; and mobilizing sources of faith, hope, and cultural traditions.

### Considering Caregiver Bereavement within the Context of an Adolescent Suicide Attempt

p. 35

#### Pamela Orren, PhD

In this article, Dr. Orren argues that: “The experience of being a caregiver for an adolescent following a suicide attempt is often harrowing and ambiguous. The bereavement process does not end when the patient medically stabilizes; in fact, it often continues for years as both the patient and their caregiver enter into longer-term mental health treatment. Normative bereavement following a suicide attempt remains unclear and varied. However, outcomes will likely be improved with increased normalization and validation of the bereavement trajectory for both adolescent patients and their caregivers.”



#### 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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

### How Honesty Heals a Community Crisis

p. 38

**Rebecca Konarz, LMSW, IMH-E**

This article begins with the following statement: “In the face of tragedy, especially an unforeseen or sudden death of a child, the first response of parents and adult caregivers is to shield their own child, or the other children in the community, from the situation. However, the best antidote to surviving community tragedy is honesty; both for you, as the parent or caregiver, and for the community of children involved.” The author goes on to acknowledge that “Honesty is difficult amidst crisis,” but she offers guidelines to “assist a community in changing a tragedy into a moment of solidarity and support, especially when it has been a child or teen who has died.”

### Crisis and Health Care Workers: What We Should Consider

p. 40

**Anna Konstantin, MSN, CNL**

Writing as someone who has worked as a bedside nurse in a pediatric intensive care unit for 11 years, the author of this article basically encourages health care workers to own their own trauma in crisis situations. As she writes, “if we do not start recognizing the trauma we are going through and begin treating that trauma, we will not stay in the field and we will not stay healthy, causing those who need us most (our patients and families) to suffer.”

### Thinking about Helping when Traumatic Events Occur

p. 42

**Patti Anewalt, PhD, LPC, FT**

This article reflects on that fact that numerous, recent, widely-publicized community tragedies have led “many who work in hospice and palliative care to wonder how they would, or should, respond if a traumatic event occurred in their community.” While acknowledging that these concerns are well-intended, Dr. Anewalt offers a caution: “Just because pediatric hospice and palliative care professionals work with dying children and their family members, does not mean they have the training, experience, or skill set to help in situations such as suicides or mass casualties in community tragedies.” She explains that caution by encouraging PPC professionals to manage their priorities, anticipate involvements, and decide how best to help. Her conclusion: “What is most important for pediatric hospice and palliative care professionals who are thinking about helping when traumatic events occur is to look at what the needs are in each situation, as well what their expertise, experience, and availability is, to determine where the best fit will be.”

### Resources for Providing Support for Children and Families Experiencing or Grieving from Crisis or Trauma

p. 44

**Compiled by Ann Fitzsimons, BS, MBA**

This article lists a broad range of “resources to help professionals who find themselves in a position to care for a child or family, who is experiencing or has experienced some type of crisis or trauma—from a suicide of a loved one or peer, to a school shooting, to a natural disaster, to some other type of personal crisis or trauma in a family. To some families, this could include caring for, and living with, a child who has a life-threatening illness.”

### Reprinted (by permission in each case) Three Sets of Guidelines for Talking to Children after a Tragedy has occurred:

#### 10 Tips for Talking to a Child after a Tragedy

p. 50

by Diane Snyder Cowan at Hospice of the Western Reserve

#### Talking with Children and Teens about Suicide and Violent death

p. 52

by Lynn M. Snyder, LPC, ATR-BC, FT, & Melissa Lunardini, MA

#### Talking to Children about Terrorist Attacks and School and Community Shootings in the News

p. 54

from the National Center for School Crisis and Bereavement ([www.SchoolCrisisCenter.org](http://www.SchoolCrisisCenter.org))



#### 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](http://www.nhpco.org/pediatrics)

Reprinted (by permission) “Interdisciplinary Guidelines for Care of Women Presenting to the Emergency Department with Pregnancy Loss” p. 56  
**National Perinatal Association**

**Trends in Pediatric Palliative Care Citation List, 2018, #3** p. 67

This citation list is generated monthly by [PedPalASCNET](#) to collect new articles in pediatric palliative care research. To see past citation lists and expert commentaries visit [their blog](#). (Note: The ChiPPS E-Journal includes this bibliography of new articles in PPC as an additional service to readers.)

#### ADDITIONAL NOTES

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics).

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

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

-###-



#### **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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

## WHERE DO I START?

**Scott Newport**  
Evan's Father  
[scottandpenni@hotmail.com](mailto:scottandpenni@hotmail.com)

Have you ever had one of those moments when you see an act of kindness that's so amazing but just can't figure out how to explain it? You don't know how to start the story or how you will ever finish, but you know the narrative must be told.

Even though I'm just a carpenter by trade, on occasion I spend time working in a pediatric I.C.U. setting with doctors and nurses. I know it sounds crazy, but I have a son who had a syndrome and is now waiting for me in heaven. Because of my seven years with Evan, I use that experience to mentor other families of sick kids. Last month I spent time with first-year medical students, teaching them about the patient and family side of medicine.

Yesterday, though, I was at a training session for parent and professional teams. The two-person teams were either from health care organizations or state agencies that help kids with special needs. The purpose of the all-day event was to develop stronger leadership attributes.

I didn't know anyone there except for Dr. D'Anna Soul, a young physician who agreed to attend with me. D'Anna and I had never spent much time together, even though we share a common mission of helping families of terminally-ill children. Our team would be representing C.S. Mott Children's Hospital at the University of Michigan. Part of the prerequisite to attending this event was to identify a project we are working on.

The project D'Anna and I are currently working on is to rename our hospice and palliative services at the hospital to "Stepping Stones."

The meeting started out with an ice-breaker—you know, one of those activities with the purpose of getting folks acquainted and making people feel less nervous.

"Ok, teams," the facilitator said. "I want you to interview someone in the room you don't know and find out what their likes and dislikes are. Find out what their hobbies are and when you get done, you will introduce your new friend to the group."

Across from D'Anna and I were two ladies. One gal had a pretty yellow dress on and the other had a briefcase plopped in front of her.

Before I knew it, the women across from me said, "Hi Scott, my name is Linda and I'm a speech therapist with *Early On*."

While I listened to Linda's story, Dr. D'Anna stood over in the corner and listened to the woman wearing the yellow, flowery dress.

When it was time for the woman in the yellow dress to introduce D'Anna, it became quickly apparent that the middle-aged woman had a severe speech impediment. (I found out later that this woman had had a stroke and struggled to form the words her mind wanted to convey).

I immediately became nervous and felt helpless to do anything even though, in my heart, I felt I should do *something*. Afraid to even look around the room, I knew everyone probably felt the same. It was like someone had shut the windows and the room would soon be suffocated.

"D'Anna go—," she fragmentally said, followed by silence.



### 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](http://www.nhpco.org/pediatrics)

Each time she tried to form a sentence it was like shoveling out heavy concrete that had been previously mixed to the perfect consistency in a wheel barrow but was now setting up, with no way to slow down the solidification.

“D’Anna go—,” the woman tried again. There was more silence, then more struggling for the right words.

Within seconds D’Anna reached out and helped her new friend articulate words in a gentle voice. I don’t think I had ever seen anything like that. With each word D’Anna spoke, filling in the blanks from the parent’s efforts, the woman’s eyes tilted up slightly in acknowledgment. Even though she didn’t smile her yellow dress seemed even brighter than it had been before.

Every time the woman said, “D’Anna go—” (which seemed to be her preferred verb), D’Anna would fill in her blanks: “D’Anna likes to read and help heal sick children.”

As soon as the two sat back down it was like a window in the room had been opened, as if a subtle September morning breeze entered the room.

The day after, I desperately wanted to write down a reflection of that moment; to write something I could share with D’Anna one day.

I guess maybe the deeper truth to this experience was how much I learned about D’Anna and how proud I am she took time out of her busy schedule to attend the training. I mean, I’m just a carpenter but we share our passion for families.

Today, I feel like I have a true partner that will never let me down. And she will surely fill in the blanks when maybe I get jammed up and don’t know the rights words to say. All I can hope is that I can be a person who opens a window for families when they suddenly find themselves feeling suffocated by the diagnosis of having a child with a complex medical condition.

-###-



**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](http://www.nhpco.org/pediatrics)

## DOUBLE THE PAIN: HOPE UNLIMITED

**Marief Nasis-Matuza, MS, RN, CPNP**

Palliative Care Team  
St. Mary's Hospital for Children  
Bayside, NY

[mnasismatuza@stmaryskids.org](mailto:mnasismatuza@stmaryskids.org)

There was nothing out of the ordinary on a Thursday afternoon for one kindergarten teacher who lives in the suburbs of New York. Her three children were home from school, and our interview was interrupted as she readied her 12- and 8-year-old boys for lacrosse practice. After the boys left with Dad, lacrosse gear in hand, Jen and I reminisced back to 2004, when her life was anything but ordinary with the birth of their first son, Brendan Brian. Little did they know that their third son, Liam Patrick, would provide the reason why Brendan did not live to see his first birthday.

Jen and Mike Shanahan, a young, handsome couple, were anxiously awaiting the birth of their first child. She was a teacher and he a member of the NY Police Department. The pregnancy progressed very well with no complications, and Jen continued working full-time until she went into labor at 38 weeks. On March 18, 2004, the couple was blessed with the arrival of Brendan Brian, weighing in at 6lbs., 8oz, and 19-1/2 inches long.

The first-time parents were in awe. Brendan was perfect, with 10 fingers, 10 toes, and beautiful blue eyes. He brought the couple so much happiness, even though he was a difficult baby from the start. Jen tried to breast feed, but Brendan was colicky, always crying and uncomfortable. Worried Brendan would not gain enough weight, they soon introduced formula. They changed formulas many times, from Similac Sensitive to Alimentum and everything in between, but Brendan didn't tolerate any formula well. "I didn't understand why," Jen said. "We tried everything."

Brendan was also constipated and frequently spit up. At this young age, he was even referred to a pediatric gastroenterologist. But because Brendan was in the 90<sup>th</sup> percentile for height and weight, Jen and Mike were always reassured that Brendan "is doing well," so they kept on going.

For the first few months, the young couple went back and forth to the pediatrician. Brendan was meeting his milestones, and besides colic and not tolerating formula well, Brendan was a good baby. But from the start, Mom knew "something was wrong with him. Something wasn't right."

At 6 months of age, little brown spots appeared underneath Brendan's armpits. Jen speculated, "I wondered if they were bug bites." She disinfected their apartment, but red lumps that looked like mosquito bites continued to appear on Brendan's arms. Curiously, there were none on his chest or anywhere else on his body. So Jen and Mike sought the advice of a dermatologist, who recommended creams.

Despite these brown spots and the challenge with his formula, Brendan was strong for his age and appeared to be meeting his developmental milestones on time, until he began tilting his head. The pediatrician diagnosed torticollis, which means "twisted neck," and recommended physical therapy. Suddenly, Jen became more cognizant of accompanying subtle signs that were concerning to her.

For example, he was not sitting up at 6 months old, and the pediatrician said he may need early intervention and therapy, but that this was not uncommon. Then Jen pointed out that one of his eyes appeared to be turning in a little, like a lazy eye. "I felt he was regressing," Jen recalled, but every time she voiced her concerns to the pediatrician, he "blew me off," saying "I was a new mom, I was overreacting," and "everything was normal." She was told that maybe because of colic, he was developing a little slower.

Despite these concerns, attributed by health professionals to the heightened anxiety and nervousness of



**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](http://www.nhpco.org/pediatrics)



first-time parents, Brendan was a happy baby. Then, at 8 months old, Jen noticed that Brendan started losing weight, and although his eyes were bluer than ever, his usually fair skin was now always flushed and his cheeks were constantly rosy. He was crying more than ever before, and he “never slept.” For Jen, this marked the time when Brendan “got sick.”

The new family moved into their first home on December 1<sup>st</sup>, 2004, and that night, Brendan wouldn’t stop crying. He was inconsolable, arching his back with an endless shrill cry. Once again, the pediatrician continued to minimize Mom’s concerns. After crying all day long, Jen and Mike decided to seek other advice and set out for the Emergency Room at a local hospital. Brendan was evaluated. His vital signs were stable, and there was no fever. Jen pointed out that his ear was very red. The health care provider indicated that this could be a possible cause for his discomfort, prescribed Tylenol and rest, and discharged the family home.

“But I had this terrible feeling that something was really wrong,” Jen recalled.

Mike refused the discharge, but realized their objections were futile. They decided to go to another hospital. As they were leaving, Brendan suddenly started twitching uncontrollably on one side of his body, most pronounced at his head and shoulder. He was immediately rushed upstairs and admitted to the pediatric intensive care unit (PICU). Despite very strong medication and high-dose sedation, the seizures continued and the medical team decided to intubate Brendan to stabilize him and protect his airway. A computed tomography scan (CT scan) of the brain revealed atrophy on one side of the brain, or a “wasting away” of the brain, similar to that of a stroke victim. Brendan remained intubated for a few more days as the medical team continued trialing different anti-seizure medications. Each time they attempted to extubate, Brendan began seizing again.

Brendan was then referred to the epilepsy center at New York University (NYU) Hospital. A neurosurgeon there determined exactly where the seizures were originating on the left side of his brain, and recommended removing that part of the brain that was causing the seizures. He explained that the right side of Brendan’s body would be affected, but the results would not be permanent and could improve with therapy.

This was the hope, the answer Jen and Mike prayed for. The surgery was successful, but after the long road to recovery, Brendan did not tolerate food. Initially, it was necessary to provide his nutrition via his veins (TPN – total parenteral nutrition). Eventually, a gastrostomy tube (GT) was surgically placed, an external tube from the abdominal wall into the stomach, for nutrition. Feeding through the GT was not tolerated, and Brendan underwent another procedure for a gastrojejunostomy tube (GJT), which allowed feeds to go directly into the small intestine.

After the brain surgery, there was little seizure activity. Jen and Mike remained hopeful, but then the seizure activity started again. Brendan was on steroids and retained water. He received numerous transfusions and blood tests showed his liver was failing. When they realized removing part of his brain was not the answer, Jen and Mike started asking more questions. The spots on Brendan’s arms were biopsied. Jen and Mike scrutinized their family history. There were no genetic disorders on either side.

Brendan’s symptoms worsened. As his liver continued to fail, Jen and Mike understood Brendan needed a new liver. They underwent testing and Mike was found to be a compatible liver donor. Arrangements were being finalized to transfer care from NYU to Children’s Hospital of Philadelphia (CHOP) for the liver transplant, but Brendan was already too sick.

“We knew he was declining rapidly,” Jen surrendered. Doctors exhausted all treatments. “I didn’t want to see him go through everything... He had no DNR, so they had to resuscitate many times. Finally they told us, even if he comes out of this, he won’t be who he was before.”

Brendan died at NYU four days before his first birthday on March 14, 2005.

Devastated, Jen and Mike did not want an autopsy. The death certificate listed “sepsis” as the cause of



### **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](http://www.nhpco.org/pediatrics)

death. They did, however, save his stem cells.

Just as they were coming to grips with the long road of heartache and pain ahead of them, they discovered in April that they were expecting. Tyler was born in November 2005. From the moment they laid eyes on Tyler, “we knew that Tyler was going to be okay. I guess it’s a parents’ intuition and sure enough we were right. Tyler was a healthy baby and was truly a gift from above,” the Shanahan’s wrote on their web page.

But in reality, “We didn’t know,” Jen admitted during this interview. “We still felt like he was going to get sick. We still saw genetic doctors.” Tyler continued to thrive and develop normally. Thankfully, Tyler didn’t suffer from colic and he never had seizures.

Soon, Tyler became a big brother as the Shanahan family was again blessed in September 2007 with the gift of Liam Patrick. He was happy, he hit his milestones and he wasn’t colicky. Then at 7 months old, Jen noticed his head tilting to one side and “I knew it,” she said. “Am I going crazy? Why is this happening all over again?” She received reassurance from her doctors; they said she was “overreacting.”

Liam finally “got sick” when he was 8 months old. Jen picked him up from a nap and felt a twitch on one side. “I knew immediately,” she declared. Once again, Jen and Mike made that all too familiar car ride to the ER where they initially took Brendan, and he was still twitching when they arrived. Without delay, the ER staff arranged a transfer to CHOP. Within hours, the family was airlifted from NY to Philadelphia where they were greeted by an entire team of doctors including geneticists and neurologists. Liam received attention immediately, and the testing on Brendan’s stored stem cells began as the team explored the possibility of a genetic disorder.

“We were given a list of things it could be,” Jen recalled. The doctors at CHOP, with Brendan’s file in hand, composed a list of possible diseases. Alpers was one of them (see end NOTES). Jen researched many of the diseases, and as she read about Alpers, she remembers saying to herself, “This one is really bad. I hope it isn’t this one.” Two weeks later, the doctors had a diagnosis: Liam had Alpers. And so did Brendan, confirmed by the post-mortem testing of Brendan’s stem cells.

Jen already knew what the prognosis was. “I did not want Liam poked and prodded, no surgeries. It was terrible what Brendan went through. I did not want all the experimental things for Liam. To live as normal a life as he could, that was our goal.” Liam did not undergo the surgeries his older brother did. There were no spinal taps, no EEGs, no biopsies, no endless blood tests, none of the invasive measures Brendan had to endure.

Jen and Mike evaluated available options and treatments, but there were no current pharmacological trials, no medicines to slow down the progression of the disease, no further testing. Nothing could be done. With heavy hearts, Jen and Mike took Liam home after being in the hospital for 2-1/2 months. He had around the clock nursing, but Jen did all of the care. “Nurses were there if I needed help,” Jen said. It was important to Jen that Liam remained in the “comfort of his own home, with us. He slept with me instead of in a hospital bed.” Her goals of making him comfortable and ensuring he was in the least possible pain were met. Jen remembers, “It was very different with Brendan.” The road was tough and frustrating because the “docs didn’t listen.” They looked at Brendan and said “this kid does not have a genetic disorder.” He looked so “normal,” and he was growing and thriving. Jen felt they had a hard time with Brendan’s doctors because they “weren’t reading between the lines.”

When they brought Liam home, Jen and Mike’s goal was to “get him to his first birthday,” something they couldn’t do with Brendan. Two months later, they celebrated Liam’s First Birthday. It was a “really happy moment” for the Shanahan family. Jen felt like he almost waited for his birthday. He was sleeping all the time at that point. He wasn’t in pain and was very relaxed, but Jen noticed his coloring “wasn’t too good.” As the family gathered around him, Liam opened his eyes for his birthday cake and “gave us a big smile. We blew out the candles, and he never opened up his eyes again.” Jen’s voice is breaking as I fight back my own tears. That was the last time he opened his eyes. Liam died in his mother’s arms in September 2008.



### **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](http://www.nhpco.org/pediatrics)

**Q: I asked Jen if she was able to talk to her parents or to Mike's parents.**

**A:** They were devastated. They didn't know what to do, and we didn't want support. We needed to make our own decisions. Both families were supportive, even our friends, but there was nothing anyone could do to make us feel better. I didn't want people trying to make me feel better. I wanted to be left alone. My husband turned to friends. I always knew when he was born... I had that gut feeling. I live with the guilt that something wasn't right with him.

**Q: Were the medical providers supportive?**

**A:** Absolutely. The experience was better with Liam. We were fighting with the docs with Brendan. We wanted to go home, but they didn't want us to go home. With Liam, we were all on the right track. The docs and nurses at all the hospitals were on the same page with the type of treatment and care we wanted. Communication between CHOP and the hospitals in NY was so good. It was just as painful with Liam, and in a way, harder the second time around because I knew what to expect. But we did better by Liam by advocating and knowing.

**Q: Did you consult religious clergy?**

**A:** No, they turned me off. There was nothing he could do to help. Mike went to the chapel and said prayers, but I didn't want to hear it.

**Q: How did you feel when doctors could not give you an answer as to why this happened to Brendan?**

**A:** Angry. They didn't read between the lines. If it didn't fit a certain criteria, they were at a loss for words. I felt that more could have been done... there was frustration with the doctors. [Brendan] was just a number. He was so sick, but yet, mom and dad were "overreacting" even though he was in critical condition every day... They didn't have the human touch and became numb to what families are going through.

**Q: Did all of this impact your marriage? How?**

**A:** It hugely impacted our marriage. Lots of ups and downs. After Brendan, we couldn't be in the same room. We couldn't talk to each other. We handle grief so differently. We really struggled. We tried counseling, but that was the worst thing we did. We separated for a bit because [back then,] being together made us angrier. We still struggle. Now we accept that we grieve differently. He does his own thing on the anniversary. He is willing to talk more than [I am]. We tried counseling but it didn't get us anywhere.

**Q: How do you cope?**

**A:** We still have ups and downs. We are handling it better, but it's still a struggle. We make sure we are not being over-protective [of our 3 children]. We are trying our best to be normal, but [it] derailed us from our life.

**Q: Tyler was almost 3 years old when Liam died. Does he remember Liam at all?**

**A:** He remembers him healthy, and sick. He remembers nurses in the house. Sometimes, he gets angry. He is afraid of getting sick. I asked if I should get Tyler counseling, but the docs said no. For the most part, he is normal, but he has his moments of being angry and upset. When he gets sick, or when the twins get sick, he is afraid something will happen.

**Q: Knowing what you know today, is there anything you would have done differently with either Brendan or Liam?**



**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](http://www.nhpco.org/pediatrics)

**A:** Most of my regrets are with Brendan. I was desperate for him to get better. In hospitals, they go overboard with testing and doing so much at once. He was non-expressive. He was not up and crying. He was so lethargic, you forget that they still feel everything being done. Taking blood, spinal taps... that poor baby. They didn't give him anything, but he didn't cry. I should have stood up more, and that's what I did with Liam. With Brendan, all procedures and surgeries... I thought he would get better. He went through so much... Dialysis, a port blew, they couldn't get a vein... The memories of what he went through are terrible. You don't want your child to be in pain. Brendan was always in pain. Liam was a happy baby, smiling and laughing. Brendan was fighting, angry. My regret is that he went through so much. Procedures, tests... were not necessary.

**Q: What do you want people to know when faced with an incurable illness?**

**A:** Always go with your gut. Doctors will tell you one thing, but that doesn't mean they are right. Be the best advocate that you can be for your child. You really need to advocate for your kid. They forget that they are little humans. The docs don't know your kid. You do.

Jen and Mike Shanahan were doubly blessed on November 10, 2009, when they welcomed healthy twins into the world, a boy and a girl, Dylan and Gabriella. Conceived through pre-implantation for genetic diagnosis (PGD) and IVF, genetic analysis before implantation ensured their children would not carry the genetic marker for Alpers. Today, Dylan and Gabriella are active 8-year-olds with a very protective big Brother!

Jen and Mike wanted to make sure Brendan and Liam's legacy lived on, so they established the **Brendan and Liam Shanahan Foundation**. "This is the only thing we have left of them," Jen expressed. Their goal is to help other families facing this devastating disease as well as raise money for funding research. After Brendan and Liam passed, their stem cells were donated to a genetic doctor at CHOP for the research he is doing. There is a clinical trial currently in progress. It may not be a cure, but hopefully it will slow down the progression of the disease. Jen's voice became bright. It "gives me hope that in the future, there will be a cure," she said.

"With Brendan, I felt so alone," Jen remembers, "in a world of not knowing what to do. After Brendan passed, we were lost, both of us. Once Liam got sick, I really started looking into other families." She was introduced to a family from London and they were in constant contact. Due to this connection, the Foundation became an instrument for uniting a network of families struggling with Alpers all around the world.

Through their Foundation, Jen and Mike became pillars of strength for so many families. They were active in their community raising awareness by organizing fundraisers and golf outings. They connected with families internationally, and the work they were doing was very important to so many, but Jen admits all the grief finally took an emotional toll.

"I was so sad for the families that reached out to me. I had to stop. I needed a break. I needed a mental break. I [couldn't] see sadness anymore. Children dying... overwhelms me with my [own] grief... knowing that pain. So I took a couple of years off. Even the foundation, events, golf outings... I needed a mental break where I can get myself back. I'm at a [point] in my life where I can get back to it now. Now, I'm like ok, I'm back. I want to help families. I want them to know they are not alone."

Welcome Back, Jen...

The loss of one child is devastating; the loss of two children unimaginable. Yet, years later, Jen and Mike Shanahan still struggle with the endless medical, emotional, social, and religious challenges of an incurable illness, death and grief. They are not alone. They encourage parents to "get all options and make the best decision for your child." They want others to hear their story and remember their sons' strength and courage. They want to touch families and make a difference. They want others to always have hope.



**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](http://www.nhpco.org/pediatrics)

**NOTES:**

Mitochondrial DNA depletion syndrome-4A, also known as Alpers syndrome, is an autosomal recessive disorder characterized by a clinical triad of psychomotor retardation, intractable epilepsy, and liver failure in infants and young children. Pathologic findings include neuronal loss in the cerebral gray matter with reactive astrocytosis and liver cirrhosis. The disorder is progressive and often leads to death from hepatic failure or status epilepticus before age 3 years (review by [Milone & Massie, 2010](#)). (OMIM® - Online Mendelian Inheritance in Man®, 2015).

**What Is Alpers' Disease?**

Alpers' disease is a rare, genetically determined disease of the brain that causes progressive degeneration of grey matter in the cerebrum. The first sign of the disease usually begins early in life with convulsions. Your child may or may not have shown some developmental delay prior to the onset of the main disease symptoms, which usually occur within the first few years of life; these may initially involve a loss of previously learnt skills and/or a sudden onset of seizures which are usually very difficult to control. The combination of the severe epilepsy and the ongoing brain disease, which is causing the seizures, leads to increasing loss of skills and awareness. The infant often develops some physical stiffness (spasticity) and subtle involuntary movements especially of hands, feet, face, and head. Another symptom includes liver problems such as jaundice and cirrhosis that can lead to liver failure. Optic atrophy may also occur, often causing blindness. The course of the disease is usually rapid and eventually the combination of the diseased brain and increasing physical weakness becomes too great to sustain life, and death usually occurs within a year. Parents will be aware of the child's increasing frailty, and death is usually relatively peaceful and expected when the time comes. Very rarely older children and teenagers may develop an apparently similar condition called Juvenile Alpers' Disease, whose course may be more protracted, over very many years. A number of individuals with Alper's disease have mutations in the "polymerase-gama" gene, which results in the depletion of mitochondrial DNA. Researchers suspect that Alpers' disease is sometimes misdiagnosed as childhood jaundice or liver failure.

(Taken from <http://brendanandliamsgift.com>)

For more information about *The Brendan and Liam Shanahan Foundation*, go to <http://brendanandliamsgift.com>

**About the author:**

Marisel Nasis-Matuza, MS, RN, CPNP, is a pediatric nurse practitioner on the Palliative Care Team at St. Mary's Hospital for Children in Bayside, NY. Marisel first met the Shanahan Family in 2008 as she took care of Liam in the PICU as his nurse.

-###-

**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](http://www.nhpco.org/pediatrics)

## WHEN A CHILD DIES IN THE EMERGENCY DEPARTMENT

**Suzanne S. Toce, MD, FAAP**

Retired Neonatologist  
Gundersen Health System  
La Crosse, WI  
[tocess@gmail.com](mailto:tocess@gmail.com)

The dying and the death of a child/adolescent are traumatic events for all involved. While any death of a child is traumatic, a sudden, unanticipated death causes profound distress in parents and other loved ones and can be associated with long-lasting grief responses. Applying basic palliative care principles in the emergency department (ED) setting that is usually focused on aggressive life-prolonging activities can improve the outcomes (Quest 2012). This approach helps consider the child as a person and part of a family, and supports interdisciplinary care.

Children contribute only 4% of all deaths occurring in the ED, or less than 1 per 15,000 ED visits (O'Malley 2014). Yearly in the US, there are ~22,000 deaths in newborns and infants, and almost 19,000 in children aged 1–19 years (Friebert 2015; Murphy 2017). In this latter group, close to 58% of deaths were from unintentional injuries, homicide, and suicide (Murphy 2017) and are more likely to present in the out-of-hospital or ED setting. The infrequency of dying and death in the ED and stress of the situation make this challenging for the ED staff.

Consider the challenges of this potential case:

*Alisha is an 8-month-old, previously healthy girl. She was seen in urgent care the previous day because of upper respiratory infection symptoms. Today, as her fever was gone, her parents took her to day care as usual. Several hours later, she had rapid onset of respiratory distress and stopped breathing. The staff started CPR and called EMS who transported Alisha to the children's hospital ED. Including in the accompanying information was the fact that the family identified itself as Muslim.*

### Care of the child

The care in the emergency department should, as always, be child-centered, family-focused, and team oriented (AAP 2014; Knapp 2005). In addition to any life supporting care, the child should receive basic palliative care with attention to pain and symptom management, and psychosocial and spiritual support. In some settings, the pediatric palliative care team may be available to assist in challenging cases. The team should also be consulted if they have previously been involved in the child's care as in the case of the child with medical complexity (CMC).

While treating the child, it is important to evaluate for possible causes of injury, illness, and/or death as indicated. Identify situations such as possibly preventable circumstances, intentional injury, concurrent family stress, suicide, etc., that might warrant concern. Have clear guidelines directing referral to law enforcement or Child Protective Services such as suspicion of sudden infant death (SIDS), abuse or maltreatment, or homicide/suicide, as well as undetermined cause of death. In any case where the cause is unknown or of questionable origin, it is important to preserve possible evidence while caring for the child and supporting the family. A protocol concerning gathering evidence and collaboration with law enforcement and Child Protective Services supports preservation of forensic evidence while treating the child and compassionately caring for the family (O'Malley 2014).

### Care of the family and others involved

**Identify the “family” and team.** It is important that a team member clarify who will be impacted by the death or potential death of this child. Identify parents, siblings, extended family members, decision



#### 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](http://www.nhpco.org/pediatrics)

makers, and others affected such as schoolmates. Determine support people in the family and community. Determine those who might be at risk for adverse reactions and complicated grief. Ensure that the parents know the identities and roles of care team members. Identify a care coordinator/key contact person who will bridge and coordinate family and team member communications. Confusing or conflicting information and lack of coordination can be major sources of family stress. The key contact person can support the family in communicating with the child's siblings and other family members. She/he can also ensure that the child's medical home and other community and hospital-based former health care providers are informed and involved, as pertinent.

**Communications.** Communications should be empathetic and strategic. While these communications are challenging and rarely taught in medical or nursing school, skills such as delivering bad news and communicating during stressful times can and should be learned (Truog 2006; Fry 2016). Parents value communications that are kind, compassionate, and honest (Meert 2008). A skilled professional such as a social worker or chaplain may be an ideal person to assess the parents' communication needs, preferences, and preferred communication style. Communications should respect social, spiritual, cultural, and ethnic diversity (Cochrane 2017). In cases where the parents are not fluent in English, utilize the services of a trained medical translator. Cultural humility is a good approach in challenging cases. Involvement by a religious or spiritual leader from that tradition may be invaluable. Start by assessing what parents know and want to know. Clarify the facts. Support a realistic review of the event and acknowledge family interventions on the child's behalf. Parents will likely want to know if the injury was preventable. Inquire about previous experiences with loss.

Ensure that information is updated periodically as appropriate. Communicate likely trajectory and prognosis as accurately as possible, neither overly optimistic nor pessimistic. Withholding accurate prognostic information undermines decision making and leads to distrust and feelings of betrayal. Support hopes but do not encourage "false hopes." Many parents express hopes such as their child won't suffer, they will be holding their child, their child won't die alone, their siblings will be by their child's side, etc.

Reporting sudden death requires special skills (Meert 2008; O'Malley 2014). Parents expect that it is the attending physician's duty to notify them if the child arrives in the ED dead or dies unattended by the parents in the ED. The attending physician should start by introducing her or himself and her or his role. Use the child's name. As able, choose an appropriate private setting, and support personnel such as chaplain, social worker, child life specialist, and nurse who was holding the child when he/she died. Prepare the parents that you will be delivering bad news. Use unambiguous language such as "dying," "death," "died." Provide basic information with plans for follow-up discussion. The physician should address the child's likely pain and suffering, treatments received, likely cause of death, and who was attending or holding her/him. Parents frequently wish to view the body and hold their child. When parents understand events leading up to and associated with the death, they may begin to feel they regain some control and may be able to face a new life without their child. Express your condolences. Acknowledge the loss and don't minimize the grief. Pause frequently to respond to questions and reactions. Provide bereavement materials, and names and contact information of staff.

**Support for the family.** Psychosocial, spiritual, and logistical support is the expected routine but is challenging in this stressful environment. For the parents, it is important to provide privacy, access, and physical contact with the child, especially during the dying process. The high-tech environment and continued treatments make it difficult for the parents to feel connected with and physically close to their child (Falkenburg 2016). This access may be very challenging in a busy ED where space is limited and other patients need attention. Parents value being in the same bed and holding their child. After death, many parents wish to wash and dress their child, aided by a nurse.

Parents should be offered attendance during treatment, including resuscitation, with the option to leave if desired. In the case of a resuscitation of their child, the parents can see that "everything was done," dispel fantasy, participate in decisions to stop resuscitation thereby limiting no longer beneficial treatment, say "good bye," and more easily grieve. Provide anticipatory guidance as to likely actions, responses, and outcome. The presence of a trained support person such as chaplain or social worker is key to this



#### **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](http://www.nhpco.org/pediatrics)

process. A hospital-wide protocol supports this process.

**Decision making.** Death of a child in the ED may happen when death is determined on arrival, during the process of resuscitation, or when no longer beneficial treatments are stopped. Deciding when the treatment is no longer beneficial is frequently challenging. Certainty of prognosis, child's quality of life, perceived degree of suffering, knowledge of the child/adolescent's preferences, and the family's religious, spiritual, cultural, and ethnic background may all affect decisions.

**The special situation of the child with medical complexity.** In one study ~14% of these deaths occurred in the ED (Guertin 2009). Ideally, the child with medical complexity will have an advance care plan accessible in the ED specifying their goals and preferences, specifically their preferences in the emergency setting (Wolff 2011). The plan may address such things as preferences concerning site of death, organ and tissue donation, post mortem examination, and care of the body and rituals after death. While not likely a legally binding document in minors, these documents usually give insight into the child and family's preference at the time when the document was completed. In some states, pediatric POLST (Physician Orders for Life Sustaining Treatment) are legal. Completing this documentation of resuscitation preferences should be considered in any case where death within the next 12 months would not be surprising. If a CMC presents in the ED, obtain any existing advance care plan/POLST and verify preferences especially desired site of death. Stabilize the child and attempt to organize resources to meet the child and family's goals.

**If death is likely.** Prepare the family (and the child if appropriate) for worsening prognosis. The goal is to avoid preventable child, parent, and staff distress and suffering (O'Malley 2014). Clarify the likely cause(s) of death. Routinely determine preferences for organ or tissue donation. There are federal mandates about notifying the organ procurement organization that will determine eligibility for donation. Families appreciate knowing whether the child is or is not a candidate for organ/tissue donation. Some bereaved parents not given the option of donation feel that they were deprived of the opportunity for something of their child to live on. Notification of the coroner/medical examiner about ED deaths is required in almost all states. In most cases, a postmortem examination is mandated. In other cases, offer the family the option of postmortem examination to gather more diagnostic and quality improvement information, and to help the family determine if there are familial reproductive or health implications. Anticipate that religious and cultural influences will influence preference for or against autopsy. Support memory making and gathering of mementoes. An organized space to keep supplies such as a digital camera, molds or print making equipment for hands/ feet, scissors to cut snips of hair, and blankets facilitates this process. Assist parents in spiritual/religious/cultural rituals. If family members are present, encourage them to hold their child during the dying process, if possible. If family presence is not possible or desired, identify a team member who can hold the child. Parents appreciate knowing who was with their child during this time. Determine family's preferences for care of the body after death including funeral or memorial, burial or cremation. Support the participation of siblings, with support of an adult, in the memorial or funeral service. Document the family's preferences in the medical record.

### After death of a child

A coordinated approach to the child's death should be the standard and is supported by American Academy of Pediatrics (AAP) protocols and guidelines (AAP 2014). Written protocols for family presence during and after resuscitation, anticipated death of a child with medical complexity, collaboration with law enforcement, best practices for completing and documenting procedures such as death certificate, organ donation, etc., should be included in ED policies and procedures. A hospital-wide patient death notification policy ensures that the medical home and all health care providers who have cared for the child are informed consistently. Resources to aid ED staff and families, such as child life, chaplaincy social work, behavioral health, or palliative care staff should be notified and mobilized. As noted above, medical examiner/coroner must be notified of all deaths as required by applicable law

It is important to continue to utilize child death review committees to determine preventable causes of childhood death. Information collected at the time of each child death should be systematically reviewed to help direct interventions to continue to decrease childhood deaths. Information on the death certificate



### 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](http://www.nhpco.org/pediatrics)



should be complete and accurate.

In the case of the child arriving in the ED dead or shortly after arrival, protocols for investigation, documentation, memory/mementoes, organ/tissue donation, and post mortem examination, and embedded bereavement ensures consistency in the care of the child and family.

The death of a neonate in the ED or diagnosis of fetal death may be experienced differently by the family and providers than the loss of an older child (Fry 2016). Less than 4% of neonatal deaths occur in EDs or an outpatient setting, leaving these providers somewhat unprepared. In addition to the other supports addressed in this article, ensure that the mother has access to follow-up medical care and support about lactation cessation and breast milk donation. The labor and delivery department, nursery, or neonatal ICU can often help as needed. Provide information about perinatal bereavement programs such as SHARE and RTS. Utilize protocols for fetal death evaluation and follow up.

**Bereavement support of the family.** It is important that follow-up bereavement support from the care team is embedded in the care provided in the ED. Without such support, parents, siblings, and other survivors “are left to navigate the grief process without the support and resources that might otherwise be available in an organization with an established bereavement program.” (Walter 2016). This process standardizes bereavement care and follow-up regardless of site, timing, or circumstance of death. A bereavement form or checklist within the medical record documents the process (O’Malley 2014).

Parents should be informed of expected follow-up contacts such as regular scheduled phone calls, and letters. In-person meetings should be offered, especially if there is a postmortem examination. Strategies to facilitate follow-up bereavement support by staff include having condolence notes in the ED so that caregivers may complete the notes close to the time of death or at a later time and can then be mailed out as scheduled. Completing condolence letters not only helps the family feel connection with the personnel who cared for their child, but also helps the staff feel a sense of closure (Thrane 2012). The bereavement checklist can facilitate coordination of bereavement efforts (O’Malley 2014).

Grief, especially after unanticipated sudden death, may overwhelm coping mechanisms. Educate family of likely future adult and child grief responses. Children, especially siblings, often have profound and prolong reactions to the death of a loved one. Coach parents on communication strategies to facilitate the child’s adjustment and suggest ways that children can participate in rituals. Inform parents of likely grief triggers and anniversary reactions (Schonfeld 2016). The chaplain, social worker, and/or child life specialist can aid in this effort.

Mobilize family and community support. Make referrals as appropriate. Provide written information about resources. Ensure that siblings’ schools have been informed of the death and schoolmates receive appropriate support (Schonfeld 2016). The key contact person is well suited to this role.

**Staff support.** The death of a child in any healthcare setting is likely the most anxiety producing event that physicians, nurses, and other ED and pre-hospital (i.e., emergency medical services) health care staff will ever experience. They must, at the same time, care for a critically-ill child, coordinate with their colleagues, and establish a supportive relationship with family members. They then may need to move on promptly to care for their next patient. Death in this setting is frequently seen as a failure. There should be formal, voluntary support and programs for ED staff and others experiencing distress. The process of staff support should validate emotional responses, ensure that all voices are heard, and may lessen moral distress. Encourage both informal debriefing and scheduled formal debriefing. A chaplain or social worker may be an ideal staff member to coordinate the latter. It is important to recognize contributions of the staff that helped the child and the parents. Facilitate staff attendance at funeral/memorial rituals. A closing ritual following the death of the child shows respect for the efforts that the staff made on behalf of the child. Below is one example (O’Malley 2014).

*“I thank everyone here for their efforts to save (child’s name)’s life. Please take a moment in*



#### **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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

*silence with me now to acknowledge our sorrow at his or her passing.... In his or her name [touching the child if appropriate] may we each be rededicated to our work."*

In the case example mentioned near the outset of this article, because the children's hospital had processes and protocols supporting ED death, outcome was a good as could be expected:

*While the medical team provided life-supporting treatment, the Muslim chaplain who was the designated key contact met the family and supported them in the room with Alisha. When severe myocarditis was confirmed and it was clear that treatments were no longer beneficial, the parents agreed to stop life support. The parents held their daughter as she died, and bathed and dressed her after death. The staff completed hand molds and collected a snip of her hair. The staff reported the pertinent information to the medical examiner. The physician reviewed with the family the requirement for an autopsy in this case of sudden death. The family declined organ/tissue donation. Planned bereavement follow-up was reviewed with the family. Following the departure of the family, there was a closing ritual with the staff. The staff contacted the primary care physician, the siblings' school, and the parent's spiritual counselor. Later that week, the chaplain facilitated a staff debriefing. When the physician, chaplain, and nurse saw the family at the memorial, the parents were sad but pleased to have been able to be with their daughter during her last precious moments.*

## Summary

There are some key aspects make ED deaths more challenging and traumatic for the staff and the family:

1. Death in the ED is a relatively rare event often with few supporting policies and procedures, and with little staff training, and
2. The death is frequently sudden and unanticipated leaving the survivors with little support, overwhelmed, and unable to cope.

To ensure the best child, family and staff experience, training in communication skills and basic palliative care should be included in ED staff education. Having protocols addressing collaboration with law enforcement and child protective services, family and staff support, and bereavement procedures, and documentation ensures consistent high-quality care of the child and support of the family, staff, and other survivors.

## Resources

American Academy of Pediatrics Committee on Pediatric Emergency Medicine, American College of Emergency Physicians Pediatric Emergency Medicine Committee, Emergency Nurses Association Pediatric Committee. Death of a Child in the Emergency Department. *Pediatrics*, 2014, 134 (1) 198-201

Cochran D, Saleem S, Khowaja-Punjwani S, Lantos JD. Cross-Cultural Differences in Communication about a Dying Child. *JAMA*. 2017 Nov;140(5). pii: e20170690.

Falkenburg JL, Tibboel D, Ganzevoort RR, Gischler S, Hagoort J, van Dijk M. Parental Physical Proximity in End-of-Life Care in the PICU. *Pediatr Crit Care Med*. 2016 May;17(5):e212-7.

Friebert S, Williams C. *NHPCO's Facts and Figures: Pediatric Palliative and Hospice Care in America*. Arlington, VA: National Hospice and Palliative Care Organization, 2015.

Fry JT, Henner, N. Neonatal death in the emergency department: When end-of-life care is needed at the beginning of life. *Clinical Pediatric Emergency Medicine*. 2016; 17(2):147-155

Guertin MH, Côté-Brisson L, Major D, Brisson J. Factors associated with death in the emergency department among children dying of complex chronic conditions: Population-based study. *J Palliat Med*. 2009 Sep;12(9):819-25.



### 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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

Knapp J, Mulligan-Smith D, and the American Academy of Pediatrics Committee on Pediatric Emergency Medicine. Death of a Child in the Emergency Department. *Pediatrics*, 2005; 115(5):1432-1437.

Meert KL, Eggly S, Pollack M, Anand KJ, Zimmerman J, Carcillo J, Newth CJ, Dean JM, Willson DF, Nicholson C. Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatr Crit Care Med*. 2008;9(1):2-7

Murphy SL, Mathews TJ, Martin JA, Minkovitz CS, Strobino DM. Annual Summary of Vital Statistics: 2013-2014. *Pediatrics* 2017;139:1 -12

O'Malley P, Barata I, Snow S. American Academy of Pediatrics Committee on Pediatric Emergency Medicine, EMERGENCY NURSES ASSOCIATION Pediatric Committee, and COLLEGE OF EMERGENCY PHYSICIANS Pediatric Emergency Medicine Committee. Death of a Child in the Emergency Department. *Pediatrics*, 2014;134:e313-e330. *This is your "go to" resource. In the appendix, there are guidelines for notifying the parents of the child's ED death, collaborative homicide investigation and evidence preservation, guide for ED bereavement checklist and memory box, protocol for the ED death of a child with medical complexity, and closing ritual for ED staff.*

Quest TE, Chan GK, Derse A, Stone S, Todd KH, Zalenski R. Palliative care in emergency medicine: past, present, and future. *J Palliat Med*. 2012 Oct;15(10):1076-81

Schonfeld DJ, Demaria T. Supporting the Grieving Child and Family. American Academy of Pediatrics, COMMITTEE ON PSYCHOSOCIAL ASPECTS OF CHILD AND FAMILY HEALTH, DISASTER PREPAREDNESS ADVISORY COUNCIL. *Pediatrics*. 2016 Sep;138(3). *Contains very helpful, practical suggestions about helping children deal with loss, support in the school setting, and self-care for pediatricians.*

Thrane S, Jones BL. Communication with families after the death of a child. *J Hospice Palliat Nursing* 2012; 14:6-

Truog RD, Christ G, Browning DM, Meyer EC. Sudden traumatic death in children: "We did everything, but your child didn't survive." *JAMA*. 2006 Jun 14;295(22):2646-54. *Very nice discussion based on a case.*

Walter MA, Limb R. Embedding Standardized Bereavement Care for All Hospital Deaths. *ChiPPS eJournal*, 2016; Issue 43, pages 25-29.

Wolff A, Browne J, Whitehouse WP. Personal resuscitation plans and end-of-life planning for children with disability and life-limiting/life-threatening conditions. *Arch Dis Child Educ Pract Ed*. 2011;96(2):42-8.

###



### 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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

## MORE THAN GRIEF: SUPPORTING TRAUMATIZED YOUTH AFTER A CRISIS

**Judith A. Cohen, M.D.**

Medical Director, Center for Traumatic Stress in Children & Adolescents  
 Allegheny General Hospital  
 Professor of Psychiatry  
 Drexel University College of Medicine  
[Judith.cohen@ahn.org](mailto:Judith.cohen@ahn.org)

### Introduction

Crisis situations such as natural or man-made disasters, terrorist attacks, school shootings, and other serious events affecting schools or communities are all too common. In the aftermath of these events, bereavement counselors often provide support for impacted youth. However, many of these youth need help with more than grief. Counselors providing services to youth after crisis situations should be prepared to address:

- 1) Immediate needs (e.g., lack of food, shelter and/or safety related to crisis; separation from family; lack of information re: family member or peer's injury or death)
- 2) Grief responses to the death of a family member or peer
- 3) Trauma responses to the crisis (which may be triggered by past traumatic experiences); and
- 4) Other significant problems (e.g., pre-existing mental health problems that were exacerbated by the crisis; needed medication was lost during crisis evacuation, etc.)

This article focuses on supporting youth's trauma responses after crisis situations. In these events, virtually all youth in the school or community have had some degree of exposure to the crisis situation. **Traumas** are shocking, scary, or dangerous events that involve threats to one's own or others' life or physical safety. Crisis situations are *potentially traumatic experiences*, but they are not the only traumas that youth experience. Trauma exposure is common with about two-thirds of all youth in the U.S. reporting exposure to traumas such as child maltreatment (sexual, physical, emotional abuse, neglect), domestic or community violence, accidents, and a third reporting multiple trauma experiences. Like adults, youth respond to traumas in different ways. Some youth who experience crisis events will develop **trauma symptoms** (e.g., those associated with Posttraumatic Stress Disorder, PTSD). One of the factors that puts youth at higher risk for developing trauma symptoms after crisis situations is having a history of previous traumas, so it is important to ask youth about their prior trauma experiences rather than assuming that the only relevant trauma experience is the current crisis situation.

Recognizing and providing early effective intervention for youths' trauma symptoms is critically important, because traumatized youth are at significantly heightened risk for other serious problems such as depression, suicidality, substance abuse, academic failure, and medical illness. Fortunately, these outcomes can be prevented through early recognition of trauma symptoms and provision of effective treatment. Several highly effective treatments are currently available for treating pediatric PTSD symptoms, and through initiatives like the SAMHSA-funded National Child Traumatic Stress Network ([www.nctsn.org](http://www.nctsn.org)) these treatments are being widely disseminated and implemented across the U.S. In fatal crisis situations (e.g., where the youth experiences the death of a family member or peer), another important reason for early recognition of trauma symptoms is that if these symptoms become chronic, they may interfere with the youth's ability to negotiate typical tasks of bereavement, a condition referred to as **childhood traumatic grief**. Thus, recognizing and responding to youths' trauma symptoms can improve bereavement counselors' ability to support youth and their families after crisis situations.



### 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](http://www.nhpco.org/pediatrics)

## Recognizing Child and Adolescent Trauma Symptoms

Trauma symptoms are grouped into five clusters: intrusion symptoms, avoidance symptoms, dissociative symptoms, negative mood and cognitive symptoms, and arousal symptoms. These symptoms are described briefly with clinical examples below, and in more detail in Table 1.

*Intrusive symptoms* include upsetting memories, images, dreams, thoughts, or reminders about the trauma. These are often accompanied by significant psychological or physical distress. For example, during a hurricane and subsequent flood, Rosie and her family were caught in their home as the waters rose. As they tried to escape, her father helped all the other family members climb to the roof but then he was unable to escape before drowning beneath the quickly rising waters. Rosie can't stop thinking about her father sinking beneath the waters, hearing her mother's screams, and agonizing while seeing images of him dying over and over. This is extremely distressing and leads to debilitating headaches.

*Avoidance symptoms* include attempts to avoid internal or external reminders of the trauma. For example, Joe witnessed a shooting at his school in which his close friend was killed; Joe was hiding beneath his desk and narrowly missed being shot himself. Joe admits that he does not like to think about these memories; when asked about it he denies feeling scared and says, "I just don't remember anything about it." He refuses to return to school. Youth who are temporarily successful at avoiding these reminders may look like they do not have any trauma symptoms.

*Dissociative symptoms* include feeling dazed, unreal, or separated from others or one's environment; these symptoms are most prominent in the early aftermath of trauma. For example, Martin's family escaped a wildfire in which friends died. He says, "It feels surreal, like I'm in a bad dream but I can't wake up."

*Negative traumatic mood and cognitions* include new negative mood (e.g., sadness, anger, guilt, etc.) or trauma-related beliefs (e.g., self-blame, loss of trust, believing the world is very dangerous, etc.). For example, after Susanna's mother and several other community members died in a plane crash, Susanna becomes very angry at adults for allowing this to happen, and believes that the whole world is dangerous.

*Arousal symptoms* include problems with sleep, concentration, irritability, anger, and increased vigilance and startle response. For example, three weeks after a fatal school explosion in which two children and a teacher were killed and others severely injured, children are back to school in a new school building. However, whenever there is a noise (e.g., school bell, someone drops something), several children start to cry (increased vigilance to trauma reminder of a loud noise).

For diagnostic purposes, during the first month after a crisis (or other trauma exposure), these trauma symptoms fall under the category of Acute Stress Disorder (ASD). If they persist beyond one month (or if they only appear more than one month following trauma exposure), they fall under the category of Posttraumatic Stress Disorder (PTSD). Self-report instruments such as the Child PTSD Symptom Scale (CPSS, <http://www.afcbt.org/materials/Downloads/CPSS-V%2003-15-17.pdf>) may be useful to evaluate a youth's current level of trauma symptoms, but should be used in conjunction with obtaining clinical information directly from the youth and caregiver.



### 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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

**Table 1: Trauma Symptoms in Children and Adolescents** (from APA, 2013)

Trauma Symptoms in Children and Adolescents	
<b>Intrusion symptoms</b>	<ul style="list-style-type: none"> <li>• Repetitive, intrusive, upsetting memories or thoughts about the trauma (in young children, may be repetitive play with trauma themes)</li> <li>• Bad dreams or nightmares about the trauma or scary dreams without recognizable content</li> <li>• Flashbacks or other dissociative reactions where child feels the trauma is recurring</li> <li>• Intense psychological or physiological distress in response to trauma reminders (reminders may be easily identifiable or idiosyncratic)</li> </ul>
<b>Avoidance symptoms</b>	<ul style="list-style-type: none"> <li>• Trying not to think or talk about the trauma or avoiding feelings associated with it</li> <li>• Avoiding people, places, things, situations or other reminders of the trauma</li> </ul>
<b>Dissociative Symptoms (especially common soon after the trauma)</b>	<ul style="list-style-type: none"> <li>• Feeling in a daze, time slowing, like self or surroundings are not real</li> <li>• Not remembering an important aspect of the trauma</li> </ul>
<b>Negative trauma-related mood or beliefs:</b>	<ul style="list-style-type: none"> <li>• Persistent negative emotions (e.g., sadness, anger, fear, horror, guilt)</li> <li>• Persistent negative beliefs about self, others, the world (e.g., can't trust adults; the world is dangerous)</li> <li>• Feeling detached or estranged from others</li> </ul>
<b>Arousal symptoms</b>	<ul style="list-style-type: none"> <li>• Trouble sleeping</li> <li>• Irritable behavior or angry outbursts</li> <li>• Increased vigilance, increased startle response (e.g., to loud noises)</li> <li>• Problems concentrating</li> </ul>

### Responding to Youth with Trauma Symptoms

*In the first month after the crisis*, no studies have scientifically established the effectiveness of a specific intervention for addressing youths' trauma symptoms. This is largely because crisis situations are chaotic and the priorities are to reestablish safety, routines, and community cohesion, rather than to conduct treatment research. Two promising practices are available to use for youth with trauma symptoms in the immediate aftermath of a crisis. The first is for delivery by trained mental health providers; the second may be delivered by bereavement counselors, educators, and others.

The Child and Family Traumatic Stress Intervention (CFTSI, <https://medicine.yale.edu/childstudy/communitypartnerships/cvtc/cftsi/>) is a 4-session intervention provided by trained mental health therapists within the first 30-45 days of initial trauma exposure. CFTSI has been shown to successfully prevent the development of chronic PTSD symptoms following exposure to other types of traumas but has not been tested in the month after crisis situations. CFTSI focuses on improving communication between parents and youth about the youth's trauma responses; and providing specific behavioral skills for youth and parent to cope with traumatic stress reactions.

Psychological First Aid (PFA, e.g., Listen, Protect, Connect:



#### 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](http://www.nhpco.org/pediatrics)

[https://www.ready.gov/sites/default/files/documents/files/PFA\\_SchoolCrisis.pdf](https://www.ready.gov/sites/default/files/documents/files/PFA_SchoolCrisis.pdf); <http://www.nctsn.org/trauma-types/natural-disasters>) is a typical approach that bereavement counselors, educators, and many other non-mental health professionals use in the first month post-crisis, particularly when trauma therapists are not available. Common elements of PFA include validating, normalizing, and providing education about the youth's trauma symptoms; reestablishing safety and normal routines; and enhancing community connections and support systems. Free online training applications are available for learning PFA, and bereavement counselors and others are encouraged to learn and use this model for youth with trauma symptoms early after the crisis.

*After the first month*, several treatments have scientific evidence of being effective ("evidence-based") for improving youth's ongoing PTSD symptoms. The following evidence-based child trauma treatments have been shown to significantly improve youth PTSD symptoms after crisis situations (e.g., CATS Consortium, 2010; Jaycox et al, 2010) and they are increasingly available across the U.S.:

Trauma-Focused Cognitive Behavioral Therapy (TF-CBT, [www.tfcbt.org](http://www.tfcbt.org)) is a 12-16 session trauma-and grief-focused model provided to youth and parents in parallel individual sessions or in group format (e.g., in schools). All components are provided to youth and parent and include: enhancing safety; education about trauma and grief impact; specific skill building; trauma narration and processing; and several grief-focused components. TF-CBT effectively improves PTSD and traumatic grief symptoms as well as depressive, anxiety, behavioral, and other symptoms. Nationally certified TF-CBT therapists can be located at [www.tfcbt.org/members](http://www.tfcbt.org/members).

Cognitive Behavioral Interventions for Trauma in Schools (CBITS, <https://cbitsprogram.org/>) is a group treatment model for middle or elementary school youth. Youth are typically screened in the school for trauma symptoms, and those with significant trauma symptoms participate in 10 group sessions during the regular school day. Parents may participate in 2-3 group sessions. Components include education about trauma impact, skills building, and trauma narration and processing (in individual breakout sessions). CBITS effectively improves PTSD and depressive symptoms; and after a large-scale community crisis, school-based group treatment was accessed far more than individual clinic-based treatment.

Trauma and Grief Component Therapy for Adolescents (TGCT-A, <http://www.cebc4cw.org/program/trauma-grief-component-therapy-for-adolescents/detailed>) is an adolescent trauma and grief-focused group treatment model that may also be provided individually. Youth are screened for trauma and grief symptoms and trained mental health counselors provide the treatment to students in group sessions within the school or other setting. Components include trauma and grief psychoeducation, skills building, trauma narration and processing, and grief-focused components. CGCT significantly improves PTSD, traumatic grief, and depressive symptoms.

More information about these and other evidence-based treatments for traumatized youth is available at the National Child Traumatic Stress Network, [www.nctsn.org](http://www.nctsn.org). This website also provides information about how to locate local therapists trained in evidence-based trauma treatments. Bereavement counselors who do not have such training are encouraged to refer youth with ongoing trauma symptoms to such therapists in order to receive trauma-focused treatment.

## Summary

Crisis situations are potentially traumatic for youth, and some youth will develop trauma symptoms in response to these events. Youth who develop PTSD symptoms are at significant risk for serious long-term mental health and medical problems that can be prevented through early identification and referral to evidence-based trauma treatment. Bereavement counselors who offer support to impacted youth in the aftermath of crisis situations can best help these youth by learning strategies related to: (1) asking about youths' prior trauma exposure; (2) identifying youths' trauma symptoms; (3) best practices for early responses to youths' trauma symptoms, and (4) referring youth with ongoing trauma symptoms to therapists who provide trauma-focused evidence-based treatments. More information about these strategies is available at [www.nctsn.org](http://www.nctsn.org)



### 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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

## Citations

American Psychiatric Association (2013), *Diagnostic and Statistical Manual of Mental Disorders*, 5<sup>th</sup> Edition (DSM-5). Washington, D.C.: American Psychiatric Publishing.

CATS Consortium. (2010). Implementation of CBT for youth affected by the World Trade Center disaster: Matching need to treatment intensity and reducing trauma symptoms. *Journal of Traumatic Stress*, 23, 699-707.

Jaycox, LH, Cohen, JA, Mannarino, AP, et al. (2010). Children's mental health care following Hurricane Katrina: A field trial of trauma psychotherapies. *Journal of Traumatic Stress*, 23, 223-231.

-###-



### 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](http://www.nhpco.org/pediatrics)



## CULTIVATING RESILIENCE

**Kathy Davis, PhD, MEd**

Director, Pediatric Palliative Care, Ethics and Education  
The University of Kansas Health System  
Kansas City, KS  
[Kdavis2@kumc.edu](mailto:Kdavis2@kumc.edu)

### Introduction

The *Merriam-Webster Online Dictionary* defines resilience as “an ability to recover from or adjust easily to misfortune or change” (Merriam-Webster Online, n.d.). The construct of resilience is an area of research that is commanding attention from parents, pediatricians, psychologists, psychiatrists, teachers, and others who care for children. Despite the growing body of research, challenges exist in achieving uniformity in resilience research due to ambiguities in definitions and terminology, methodological inconsistencies in studying resilience, and variability in measurements to determine if resilience exists in an individual (Luthar et al., 2000). Certainly, focused attention on these concerns is warranted to ensure that resiliency research is robust and meaningful. Despite these concerns, the importance of helping children and families recognize the value of developing resiliency demands prompt attention.

All children experience stress, often beginning as early as the first day of childcare when the infant is separated from its parents for the initial time. School, friendships, athletics, household chores, siblings, and even parents themselves may contribute to a child’s stress. For the past 30 years, research has suggested that the resources a child employs to cope with stress and the way that the youngster copes may result in positive growth and development or result in psychological problems (Compas, 1987).

For children with chronic or serious illness or injury, the effects of stress may pose greater challenges than for healthy peers due to the potential traumatic events that are inherent in the serious illness experience. The National Child Traumatic Stress Network describes pediatric medical traumatic stress as a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences. Medical trauma may occur as a response to a single or multiple medical events (Retrieved March 29, 2018; Stuber et al., 2006).

The prevalence of children with chronic illness varies widely among investigations, but is estimated that between 10% and 20% of all children have a chronic illness (Janse et al., 2005). Young people with serious chronic illness are reported to experience emotional, behavioral, and psychiatric conditions more often than their healthy peers (Knapp & Harris, 1998). However, more recent studies suggest that resilience is common in seriously-ill children and psychiatric difficulties are not inevitable (Rutter, 2006; Hilliard et al., 2015; Kearney et al., 2015).

Resilience is beneficial to the child with a serious illness, to their family and to the prosperity of any society. Research suggests that some children develop resilience while others do not. In addition, resilience in childhood has been associated with positive family functioning and resilience in parents. Understanding how to help children with serious illness develop resiliency may help those youngsters develop to their full potential (Center on the Developing Child, *Resilience*, n.d.).

### Defining and Understanding Resilience: Successes and Challenges

Resilience, in and of itself, is not a new concept. A PubMed search yielded a citation for an article published in 1948 entitled *The Amazing Resilience of Children* (Audric, 1948). Over 40 years ago, researchers began to study characteristics of children who seemed to be invulnerable and who developed positive outcomes despite difficult circumstances (Anthony, 1974). Other investigations substituted the word “invincible” for “invulnerable,” but also found that some children flourished amid difficulty while others did not (Werner & Smith, 1982). Another research direction focused on the observation that some



#### 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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

protective factors which led to positive outcomes after adversity actually originated external to the individual (Rutter, 1979; Garmezy et al., 1984). During the 1980s, the child, family, and community (school, friends, etc.) were examined in an attempt to identify the protective factors in each of those environments which promoted resilience in a child (Fleming & Ledogar, 2008).

The construct of resilience as it relates to children with chronic or life-limiting conditions is, however, a relatively new area of focus. Broadly defined, resilience connotes the *maintenance of positive adaptation by individuals despite experiences of significant adversity*. Critics of the construct of resilience cite the ambiguities in the definition of the term, the discrepancies in methods of studying resilience, the lack of uniformity in measuring whether or not resilience exists in an individual, and the heterogeneity of risks and competence in those who are believed to have resilience (Luthar et al., 2000). Research on specific diagnoses such as asthma, cancer, sickle cell disease, cystic fibrosis has resulted in resilience models for specific disease populations (Koinis-Mitchell et al., 2004; Landolt et al., 2009; Hilliard et al., 2015). Because of inconsistencies, however, generalizable research methodology across diagnoses has not been developed (Hilliard et al., 2015). As a result, some researchers question whether or not it is feasible or useful to consider resilience as a sound theoretical construct (Luthar et al., 2000).

The definition of resilience has also been inconsistent between studies. The lack of a standardized working definition has thwarted development of usable and specific strategies to enhance development of resilience. Resilience may be conceptualized as either a stable personal characteristic or trait compared with adaptive behaviors or as strategies that could possibly be modified or enhanced with appropriate interventions. Researchers have used various combinations of school attendance, intellectual capacity, parental support, family connectedness, social competence, peer support, religiosity, coping styles, optimism, and self-advocacy, among others (Bachanas et al., 2002; Alriksson-Schmidt et al., 2007; Koinis-Mitchell et al., 2012; Yi-Frazier et al., 2015).

Despite the lack of a standardized definition and inconsistencies in research methodologies, resilience itself has proven resilient to the adversity it has faced. Interest has grown in determining how to help seriously-ill children not just cope with serious illness, but to thrive despite living with a serious illness. During the past three decades, the research related to resilience in children with serious illness has intensified. Developmental and health psychologists have focused on eliminating the inconsistencies and ambiguities related to a deeper understanding of resilience.

Ann Masten (2001) suggested that there was nothing extraordinary about a youngster's ability to achieve developmental milestones while surrounded by major adversity and described such abilities as "ordinary magic." Others in the field of pediatric psychology researched youngsters with serious illness and the concomitant stressors, noting that many children and their family members adjusted well emotionally and behaviorally, had good health outcomes, and went on to live healthy, happy, satisfying, and productive lives (Hanson et al., 1987; Wallander et al., 1989; Stewart et al., 1997).

An initial step in developing resilience is to learn to cope with threats which are manageable and, therefore, not harmful. Children have many opportunities to master manageable stress when they have the support of trusted adults. Positive stress leads to positive coping which, in turn, opens the door for the development of resilience. This chain promotes personal growth and enables us, over time, to cope with life's obstacles and hardships, both physically and mentally (Center on the Developing Child, *Resilience*, n.d.).

In 2015, Hilliard and colleagues recommended a definition of resilience in the hope it would become the foundation for future work on the topic in pediatric psychology. In a special issue of *The Journal of Pediatric Psychology* (2015), the authors encouraged the field to adopt this working definition as it relates to the development of resilience in the face of trauma of serious illness of a child.

In the context of pediatric/health psychology, resilience is the demonstration of emotional, behavioral, or health outcomes that match or surpass normative developmental milestones, behavioral functioning, or emotional well-being, despite exposure to the substantial challenges of living with and managing a medical or developmental condition.



#### **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](http://www.nhpco.org/pediatrics)

Despite the continuing quest to identify a strong, all-inclusive definition of resilience for use in research and in the description of resilience, there is agreement of an association between coping and resilience. Investigations agree that positive coping must exist in family members in order for a family unit to achieving good family functioning and resilience. Adaptive coping strategies have been linked to persons with resilience (Yi-Frazier et al., 2015), task-oriented coping was positively related to resilience and emotion-oriented coping was associated with low resilience (Campbell-Sills et al., 2005). In addition, connections have been identified between the way a parent copes and how their child copes (Luthar et al., 2000; Rutter, 2006; Compas et al., 2012). Parent and child positive coping with a serious illness may be predictive of resilience in family functioning (Bellin & Kovacs, 2006; Nabors et al., 2015).

### Parental Coping

Child coping cannot be adequately addressed without first understanding parental coping. Connections and associations have been identified between the way a parent and child coping strategies. In addition, parent and child positive coping with a serious illness may be predictive of resilience in family functioning (Nabors et al., 2015).

Both children and adults have the capability to develop or strengthen resilience at any age. Such activities as regular physical exercise, stress-reduction practices, and programs that actively build executive function and self-regulation skills can improve the abilities of people of all ages to cope with, adapt to, and even prevent adversity in their lives. Parents or other caregivers can best model healthy coping behaviors for their children when they strengthen these skills in themselves ((Center on the Developing Child, *Resilience*, n.d.).

When a child is diagnosed with a serious illness, parents may not have time or energy to assess their existing coping strategies. Rather, the new diagnosis, needs of the seriously-ill child and his or her healthy siblings, maintaining the house, continuing to work, and other obligations may require the parent and child to utilize existing coping strategies rather than cultivate better, more positive methods. Those who are caring for the child and family, both personally and professionally, may be in a position to introduce effective coping methods to parents in the interest of sharing those positive coping strategies with their child. By addressing child and parent coping while also observing family resilience, caregivers may develop a comprehensive picture of family strengths and needs and be better equipped to provide the support needed by the family (Drotar, 1997).

Coping has been conceptualized as “an organizational construct used to encompass the myriad actions individuals use to deal with stressful experiences” (Skinner et al., 2003, p. 217). Some common coping strategies include relaxation (breathing, progressive muscle relaxation, guided imagery, meditation), distraction from painful stimuli, support from parents and other key persons in the child’s environment, journaling, faith, positive attitude toward illness, appropriate opportunities for child to be a decision maker, and problem solving (Harbeck-Weber et al., 2003; Kazak et al., 2003; Blount & Loiselle, 2009).

Children’s coping effectiveness has been linked to parental coping strategies and effectiveness. Several investigations have associated maternal coping styles with similar coping strategies in their children (Skinner & Zimmer-Gembeck JJ, 2007; Brenning et al., 2012, Compas et al., 2014) and, more recently, interconnectedness between father’s and children’s coping has been observed (Monti et al., 2017). Parents’ coping may also be enhanced when they feel confidence in and support from the health care team. Trust in the team’s ability and confidence that their child is in good hands may enhance coping in parents and their child (Compas et al., 2012).

Parents often attempt to add on the intense nature of caring for a seriously-ill child while trying to continue other duties associated with being the head of household. During these times, support from extended family members may enhance family coping (Knafl et al., 2013). Grandparents, aunts and uncles, and even older siblings can help with tasks that parents cannot accommodate while caring for their child with a serious illness. Similarly, allowing the child with the illness to contribute to the family may also result in the development of characteristics that can strengthen the child’s and family’s resilience. Attending school



#### 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](http://www.nhpco.org/pediatrics)

when possible, maintaining normal discipline practices, continuing to do household chores, and engaging in everyday activities of childhood may support coping (Atkin & Ahmad, 2000). Additionally, a unique and close bond may form between parent and the seriously-ill child as the parent provides care and nurturing to the child. During this time, the parent has the opportunity to observe the child's needs and respond to those needs by helping the child develop coping skills (Smith et al., 2015).

In an effort to support the child with a serious illness, parents may establish positive coping strategies as they realize the child is observing them and following their lead. These positive behaviors, initiated for the benefit of their child, may lead to a natural continuation of positive coping which, in turn, enhances family functioning and resilience (Nabors et al., 2016). Parents who do not become engulfed in their child's illness and who continue to balance the child's needs with the needs of other family members, may be more resilient. Maintaining flexibility, adapting to medical procedures, working on communication with one's spouse and significant others, and continuing daily routines are characteristics of the requisite balance to achieve resilience (Smith et al., 2015). The single most common factor for children who develop resilience is at least one stable and committed relationship with a supportive parent, caregiver, or other adult (Center on the Developing Child, *Resilience*, n.d.).

### Child Coping

A few decades ago, parents and health care providers often opted to hide the diagnosis of a serious illness from the child in an attempt to protect the child from worry and fear. However that practice, although borne out of kindness, proved to be a great disservice to the child. The youngster knew something was wrong, but was unable to name it or to learn how to cope with pain, symptoms, and changes in daily routine. Today there is much more transparency and honesty in communication with children about their serious illness, albeit variable between families based on personal beliefs, culture, and practice.

Some children engage in "wishful thinking" or hoping the disease will just go away. Others work to deny the diagnosis and to avoid the stress associated with it. These practices are known as avoidance coping and may lead to more significant psychosocial problems over time such as disengaging from activities and the resulting lack of friendships, supports, and sense of accomplishment associated with the activities; distress, depression, and anxiety for the child and his or her parents; and "catastrophizing" or believing the worst outcomes are inevitable. Avoidance coping prevents positive coping from developing and parents and health care providers should be aware of the negative potential effects of this form of coping in order to identify methods of aiding a more effecting coping approach (Compas et al., 2012).

Effective coping is active coping in regard to medical procedures, illness-related stressors, and the seriously ill child's emotions. This form of coping can be best achieved when the child and family seeks support from others, engages in distraction or relaxation strategies during procedures or stressful situations, and redefines the illness from a perspective of an uncontrollable stressor to one of a part of daily life that one must cope with (Compas et al., 2012). Positive coping is also developed through communication between the child and parent, the child and health care providers, physical touch (hand holding, rubbing back) by the parent during medical procedures, positive self-talk ("I can do this," "I will finish this and then play a game with Dad," etc.), relationship development with health care providers leading to the child feeling comfortable asking them for assistance or information during a procedure, and connecting (especially for teens) with other young people with similar health issues through camps, online support groups, or other venues (Harbeck-Weber et al., 2003, Wolchik & Sandler, 2013). Positive, active coping paves the way for resiliency and post-traumatic growth, or the growth that occurs when one overcomes adversity.

### Resilient Families

Resilience includes a variety of concepts including benefits to mental health and psychological well-being (Bellin & Kovacs, 2006) and the ability to withstand and rebound from disruptive life challenges (Walsh, 2012), resulting in the family being stronger and more resourceful in coping efforts (Rolland & Walsh, 2006). Resilience can be viewed as a common part of human adaptation which enhances growth in



#### 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](http://www.nhpco.org/pediatrics)

individuals and in families (Masten, 2001).

The most successful models to boost families' opportunities to develop resilience are those that provide information and education on resilience and coping to all family members including the child with a serious illness, parents, siblings, and extended family. This research is ongoing and it continues to be refined as new information is known. Nabors and colleagues (2016) advocated for resiliency research that examines the idea of synergy through the examination of the relationship between positive child and family functioning in the face of adversity like that experienced by children with serious illness and their families.

### Guidelines for Developing Resilience in Children and Families

Although the research is on-going in an effort to create resiliency models, there is enough evidence now to identify potential strategies or aspects of care that may benefit some children and families. The following list includes some of the findings from research as well as anecdotal experiences. Individual children and families will present with unique needs and, therefore, require specific sources of support for developing resilience. This list is intended to offer ideas for consideration. Health care providers and families are encouraged to use strategies that seem appropriate for their unique circumstances, discard those that are not germane to their needs, and add strategies that have been effective in other situations. As in all traumatic situations, the goal is to lessen the long-term effect of a traumatic experience with a serious illness or injury while realizing that some long-term effects – positive and negative – are unavoidable. The strategies have been grouped according to the 4 broad categories suggested by Harvard University's Center on the Developing Child ((Center on the Developing Child, *Resilience*, n.d.).

1. Facilitating supportive adult-child relationships;
2. Building a sense of self-efficacy and perceived control;
3. Providing opportunities to strengthen adaptive skills and self-regulatory capacities;
4. Mobilizing sources of faith, hope, and cultural traditions.

### Strategies for Developing Resilient Children with Serious Illness

#### 1. Facilitating Supportive Adult-Child Relationships

- a. **Accepting and Encouraging Support from Family and Close Friends** – It is often said that it takes a village to raise a child and that is especially true if the child has a serious illness. In addition to accepting help from one's community, the family's close circle of support is often critical to effective family functioning and the development of resilience. In addition, enabling family and close friends to have positive, helpful interactions with the child and family may serve to strengthen relationships.
- b. **Social Support** – Families may benefit from a wide circle of support including not only family, but also neighbors, other parents of children with serious illness, friends, work associates, and community members (i.e. contacts at school, places of worship, athletic teams, activities, etc.). By developing a "team" caring for the child with serious illness and his or her family members, family functioning may improve as parents are able to free up time to address the needs of the child with a serious illness, siblings, one another, the household and work. Asking for help may be difficult for some children and families but offers to help are usually genuine. For some families, requests made on social media may be easier. In this method, the parent may state, "Many have asked how they can help us while we are navigating Johnny's medical needs. The following list includes tasks and needs that we are, currently, struggling to keep up with. Thank you, sincerely, for your willingness to help us. It is greatly appreciated."
- c. **Effective Communication** – Communication is a key element in developing resilience after trauma. In order to ensure that communication is optimally effective, it must be ongoing and occurring amongst all key parties including the child, the parents, and the health care team. In addition, providers should ensure that communication is



#### 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](http://www.nhpco.org/pediatrics)

developmentally appropriate for the individual child. The child's teacher(s), child care provider, developmental pediatricians, psychologists, or child life specialists may provide assistance in general developmental principles of effective communication with a youngster or may provide direct support in communicating with the child if there are concomitant issues such as a learning disability, intellectual giftedness, language delay, global developmental delay, autism, or other developmental consideration. Special considerations include helping the child understand his or her diagnosis and treatment plan, what to expect during procedures or hospitalization, explaining the roles of various health care providers, helping the child recognize that his or her questions are important, teaching the child how to ask questions, helping the child identify who can provide more information or to whom they may go to talk about their concerns and fears.

- d. **The Other Side of Communication: Listening** - Communication has not been completed after two or more people have spoken to one another. Talking is only half of the communication process; the other half is listening. For a child with a serious illness to experience positive outcomes or to become resilient, that child first needs to be heard and understood. The youngster needs people to listen to their concerns, needs, hopes, and ideas regarding coping. Depending on the child's developmental stage, the child may find it difficult to articulate their concerns and fears. Having a parent who listens to the child, and then helps them formulate a survival plan, is critical to developing positive coping. When children do not feel heard, they stop talking. In addition, children need opportunities to develop their own listening skills and may benefit from listening to their parents' concerns. Through this process, child and parent may recognize that they share some of the same feelings.
- e. **Provide Guidance in Positive Coping Strategies** – Children, and some parents, do not automatically know how to develop positive coping skills nor how to become a resilient individual. Health care providers can help children and parents learn positive coping strategies. Parents can share preexisting positive coping skills with their child. Parents and children with serious illness have challenges in discerning the sometimes subtle differences between being hopeful but not encouraging the child to have unobtainable hope, while also encouraging being realistic while not overwhelming the child with too much information. For example, encouraging a child with a serious illness to continue to dream of being a professional football player does not promote positive coping, but helping the child research careers such as a sports agent, color commentary sports announcer, or a sports researcher may lead to recognizing their strengths and limitations and developing resilience in the process. Similarly, providing information about possible health outcomes, prematurely, may cause the youngster to be fearful, depressed, or give up. Parents may benefit from professional support in guiding their child toward a realistic, but positive, coping style.
- f. **Practice Discipline** – All humans must learn to be accountable for their actions. Enabling the seriously ill child to escape accountability may be one of the most deleterious barriers to the development of resilience. Sitting in time out does not exacerbate the child's symptoms. Rather, it provides the reminder that they are a growing, developing human being and that they are capable of being responsible and accountable. Responsible, accountable individuals are more likely to be resilient and recover from trauma. Children, including those with serious illness, need parents and parenting.
- g. **Allow Mistakes** – It is inevitable that every child makes mistakes along the way to adulthood. In the quest to enable the child with a serious illness to achieve optimal growth and development, the same opportunity should be afforded to him or her. The child should be allowed to experience positive growth when allowed to extend himself/herself as much as possible while being educated to recognize when an activity may constitute danger. A natural response of adults caring for children with serious illness is to "rescue" the child before they are harmed (physically, emotionally; psychologically). But it is a disservice to any child to rob them of the opportunity to learn from their mistakes. Health care providers might caution parents to try to avoid becoming



### 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](http://www.nhpco.org/pediatrics)

the “helicopter parent,” swooping in to rescue the child from all difficulties. Similarly, parents of seriously-ill children should allow themselves to make mistakes in parenting their child. Being vigilant and focused on perfection in parenting may detract from the family’s ability to become resilient as they learn from normal missteps along the way.

- h. **Protect the Child from Too Much Information** – The balance between honest communication and protecting the child from hearing more than he or she is capable of understanding is very important. Developmental considerations should guide the amount of information that a child receives. For example, telling the 3-year-old, at diagnosis with leukemia, that a relapse in the future means she will require long hospital stays is terrifying and, at that point in time, irrelevant. Parents may need to be reminded to take care when discussing the diagnosis and treatment around children. In the interest of honest communication, honestly answering a child’s questions, while refraining from additional comments, is usually a good practice. Resiliency cannot exist in the midst of fear and confusion.

## 2. Building a Sense of Self-Efficacy and Perceived Control

- a. **Teaching the Child Self-Advocacy Skills** - Children and teens often struggle to understand their own concerns, much less how their opinions may be perceived by adults. Feeling that their concerns may be minimized by their ultimate health care decision makers may negatively impact coping or the development of resilience. It may also result in getting “stuck” in their concerns and, thus, re-traumatization throughout the serious illness and treatment. Learn to respect their opinions, understand their needs, and practice self-advocacy. Specific attention regarding teaching children with serious illness to advocate for themselves may prove particularly essential for children who have not had a voice in decision making prior to their illness or injury.
- b. **Providing Opportunities to Make Choices** – Whether it is a 2-year-old choosing between an orange or strawberries for a snack or the adolescent who is asked to assent to an elective procedure, giving choices throughout treatment may enhance the child’s ability to develop positive coping and resilience despite traumatic events that occur.
- c. **Staying Engaged in Activities and School** – Growing up under the cloud of a serious illness and the potential trauma associated with the diagnosis may negatively impact the child’s social, emotional, and psychological development. In order to support positive development, to the greatest extent possible, the child needs to be engaged in typical activities of youth. School, sports (if possible), Girl or Boy Scouts, music classes, and places of worship are some of the environments that may normalize the life of a child with a serious illness. Staying engaged in established friendships and having the opportunity to make new friends may also be critical as friends are part of the support system that enhances coping and resiliency.

## 3. Providing Opportunities to Strengthen Adaptive Skills and Self-Regulatory Capacities.

- a. **Anticipatory Guidance** – For the youngster with a serious illness, coping with painful procedures, fear-provoking events, or bad news is difficult under the best of circumstances. However, it is especially frightening if the child is unprepared. Providing support for the child and parents before the event may serve to reduce negative outcomes. Preparation might include discussion of what to expect, teaching relaxation strategies, or engaging the child in choosing a distraction technique for an upcoming procedure.
- b. **Practice Patience** – It is inconceivable to consider any family member of a seriously ill child not experiencing times of impatience or frustration. Those feelings are an integral part of the experience and accepting that they will occur may enable family members to recognize the feelings when they arise and to know how to respond. Each member of



### 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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

the family should be encouraged to anticipate that all family members are likely to have times of heightened stress and to accept that those feelings are okay.

- c. **Relationships 101** – As family members are practicing patience, it may also be a good time to reflect upon close relationships and repair past misunderstandings with one another. Siblings may be jealous of one another (the child with serious illness may wish they could do what their siblings are able to do, while siblings may resent the gifts and attention that their brother or sister with serious illness receives). There may be little time to focus on marriage and these relationships may be put on the back burner as more immediate issues demand attention. Health care providers can encourage families to plan positive, fun family activities that include the entire family with a focus on enjoying the time together, whether it is a preferred activity or simply a family meal at the hospital. Sharing activities as a couple is important for parents and getting away for some “down” time is imperative for the single mom or dad. Similarly, parents can schedule special one-on-one time with the child’s siblings to ensure that brothers and sisters are aware of their importance in the family.
- d. **Balancing Life** – Balanced coping (Cohen, 1999) describes a place where the family can see themselves not as a victim to an illness, but as having the ability to influence the illness, its process, course, and outcomes. Maintaining balance in life can prevent the family from focusing entirely on the illness and, thus, prevents the illness from becoming the central theme of the family. As a result, family functioning and resilience is more likely to be strengthened when the illness “knows its place”.
- e. **Practice Relaxation** – Children with serious illness and their parents are drawn in by stress and negative thoughts because of what is occurring in their daily lives. In order to counteract those feelings and thoughts, family members must consciously practice positivity. Laying the foundation for practicing positivity is enhanced by physical relaxation strategies. Some options include breathing for relaxation, progressive muscle relaxation, Tai Chi, yoga, guided imagery, self-hypnosis, and mindfulness. Each of these strategies may improve positive coping and enhance resilience.

#### 4. Mobilizing Sources of Faith, Hope, and Cultural Traditions.

- a. **Individual or Family Support Groups** – It may be helpful to have opportunities to talk with others who have experiences and challenges similar to our own. Support groups provide a mechanism for persons with similar experiences to connect. Such groups may exist through the child’s medical treatment facility, in the community, or online. The medical social worker can help identify groups that are appropriate for a child or family’s circumstances. In addition to groups, individualized counseling may also be beneficial.
- b. **Religion or Faith-Based Organizations/Groups** – Religious coping has been identified as a source of support for some individuals and families who have experienced trauma. Most hospitals provide chaplaincy services or pastoral care departments within the institution. Others encourage visits from the individual’s faith leader. Health care providers may also connect patients and families with leaders from their faith community or provide information on locations for reflection, prayer, or religious services on site.
- c. **Maintain Hopefulness** – Both sides of the coin – realism and hopefulness – have a place in the trauma associated with serious illness in a child. Being realistic may sometimes be painful. For some families, adding a dose of hopefulness may be what is needed. Hopefulness always is appropriate, regardless of the child’s health situation. What one hopes for may require frequent assessment and modification, adjusting one’s hopes upward or downward, as indicated. When parents express hopefulness, children learn to maintain hope, too.
- d. **Maintain Realism** – Balancing hopefulness and realism sometimes requires alertness and diligence. It is not helpful to ignore either concept and the child will not be benefitted by an over emphasis of either. Older children and parents can employ realism by learning about the illness, recognizing possible limitations, and they can then employ hopefulness



#### 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](http://www.nhpco.org/pediatrics)



by using that knowledge to inform positive coping. Even younger children may begin to develop a healthy understanding of the realism of their illness while remaining hopeful for positive parts of the experience. With realism comes the ability to move toward acceptance and with acceptance, the child and family becomes more resilient.

- e. **Emphasize the Good** – It is typical for humans to remember the negative occurrences in life more readily than the routine or good events they have experienced. In order to ensure that a child with serious illness has the opportunity to recognize the good in their lives and to frame their experiences in a positive light, adults may provide concrete examples of the positives that surround them. A beautiful sunset, the card sent by an old friend, or not having a needle stick at clinic today are all examples of positivity that may help a child reframe his or her experiences. A child with positive images of his or her life is better equipped to develop positive coping skills leading to a strong, resilient child.

## Conclusion

Research in the development of resilience after trauma is a growing area of inquiry which has provided guidance regarding strategies to enhance positive coping and resilience. Children with serious health conditions need support to learn positive coping skills which may enhance the development of resilience leading to positive outcomes. Parents have a significant responsibility to act as their child's teacher of positive coping strategies and as their guide in developing resilience. Similarly, health care providers are uniquely positioned to observe parents' coping and assist them in strengthening their coping skills so they are better equipped to help their child.

A uniform definition of resilience in serious childhood illness and study methodology that can be standardized across diagnostic categories is requisite to ensure research results which can be generalized. Future research directions may include evaluation of the strategies recommended here to determine those which are most closely associated with the development of child, parent, and family resilience.

The advantages of developing resilience in children with serious illness are significant for the child, their family, and society. This article provides suggestions for specific strategies that may enhance development of resilience.

## References

- Alriksson-Schmidt AI, Wallander J, Biasini F (2007). Quality of life and resilience in adolescents with a mobility disability. *Journal of Pediatric Psychology*, 32, 370–379.
- Anthony EJ (1974). The syndrome of the psychologically invulnerable child. In: Anthony, E.J., Koupernik, C. (Eds.). *The Child in His Family: Children at Psychiatric Risk*. New York: Wiley; 529-545.
- Atkin K & Ahmad WI (2000). Family care-giving and chronic illness: How parents cope with a child with a sickle cell disorder or thalassemia. *Health & Social Care in the Community*, 8(1), 57-69.
- Audric, J (1948). The amazing resilience of children. *J Med World*, 69(11):329-31.
- Bachanas PJ, Morris MK, Lewis-Gess JK, Sarett-Cuasay EJ, Flores AL, Sirl KS, Sawyer MK (2002). Psychological adjustment, substance use, HIV knowledge, and risky sexual behavior in at-risk minority females: Developmental differences during adolescence. *Journal of Pediatric Psychology*, 27, 373–384.
- Bellin M., & Kovacs PJ (2006). Fostering resilience in siblings of youth with a chronic health condition: A review of the literature. *Health and Social Work*, 31(3), 209-216.
- Blount RL & Loiselle KA (2009). Behavioural assessment of pediatric pain. *Pain Res Manag*;14(1):47-52.
- Brenning K, Soenens B, Braet C, Bal S (2012). The role of parenting and mother-adolescent attachment in the intergenerational similarity of internalizing symptoms. *Journal of Youth and Adolescence*, 41(6), 802–816.
- Campbell-Sills L, Cohan SL, Stein MB (2006). Relationship of resilience to personality, coping, and psychiatric symptoms in young adults. *Behaviour Research and Therapy*, 44(4), 585-599.
- Cohen MS (1999). Families coping with childhood chronic illness: A research review. *Families, Systems,*



### 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](http://www.nhpco.org/pediatrics)

- & Health, 17;149-164.
- Compas BE (1987). Coping with stress during childhood and adolescence. *Psychol Bull*;101(3): 393-403.
- Compas, BE, Jaser SS, Dunn MJ, & Rodriguez EM (2012). Coping with chronic illness in childhood and adolescence. *Annual Review of Clinical Psychology*, 8, 455-480.
- Compas BE, Desjardins L, Vannatta K, Young-Saleme T, Rodriguez E M, Dunn M, Bemis H, Snyder S, Gerhardt CA (2014). Children and adolescents coping with cancer: Self- and parent reports of coping and anxiety/depression. *Health Psychology*, 33(8), 853–861.
- Dervishalija E & Murati E (2014). Families of children with developmental disabilities: Perceptions and experiences of adolescent siblings of children with developmental disabilities. *European Scientific Journal*, 10(2), 129-142.
- Drotar D (1997). Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: what have we learned? What do we need to know? *J Pediatr Psychol*;22(2):149-65.
- Fleming J, Ledogar RJ (2008). Resilience, an evolving concept: a review of literature relevant to aboriginal research. *Pimatisiwin: A Journal of Indigenous and Aboriginal Community Health*, 6(2):7–23.
- Garnezy N, Masten AS, Tellegen A (1984). The study of stress and competence in children: A building block for developmental psychopathology. *Child Development*;55:97–111.
- Hanson CL, Henggeler SW, Burghen GA (1987). Social competence and parental support as mediators of the link between stress and metabolic control in adolescents with insulin-dependent diabetes mellitus. *Journal of Consulting and Clinical Psychology*, 55, 529–533.
- Harbeck-Weber C, Fisher JL, & Dittne, CA (2003). Promoting coping and enhancing adaptation to illness. In M. C. Roberts, Ed. *Handbook of Pediatric Psychology* (3<sup>rd</sup> ed.; pp. 99- 118). New York: Guilford.
- Hilliard ME, McQuaid EL, Nabors L, Hood KK. (2015). Resilience in youth and families living with pediatric health and developmental conditions: Introduction to the special issue on resilience. *J Pediatr Psychol*;40(9):835-9.
- Janse AJ, Uiterwaal CSPM, Genke RBB, Kimpen JLL, Sinnema G (2005). A difference in perception of quality of life in chronically ill children was found between parents and pediatricians. *J Clin Epidemiol.*;58:495–502.
- Kazak AE, Cant MC, Jensen MM, McSherry M, Rourke MT, Hwang WT, Alderfer MA, Beele D, Simms S, Lange JF. (2003). Identifying psychosocial risk indicative of subsequent resource use in families of newly diagnosed pediatric oncology patients. *J Clin Oncol*, 21(17):3220-5.
- Kearney JA, Salley CG, Muriel AC (2015). Standards of psychosocial care for parents of children with cancer. *Pediatric Blood & Cancer*, 62 (S5). Supplement Article.
- Knafl KA, Deatrick JA, Knafl GJ, Gallo AM, Grey M & Dixon J (2013). Patterns of family management of childhood chronic conditions and their relationship to child and family functioning. *Journal of Pediatric Nursing*, 28(6), 523-535.
- Knapp PK, Harris ES (1998). Consultation-liaison in child psychiatry: A review of the past 10 years. Part I: clinical findings. *J Am Acad Child Adolesc Psychiatry*;37(1):17–25.
- Koinis-Mitchell D, Klein Murdock K, McQuaid EL (2004). Risk and resilience in urban children with asthma: A conceptual model and exploratory study. *Children's Health Care*, 33, 275–297.
- Koinis-Mitchell D, McQuaid EL, Jandasek B, Kopel SJ, Seifer R, Klein RB, Potter C, Fritz GK (2012). Identifying individual, cultural and asthma-related risk and protective factors associated with resilient asthma outcomes in urban children and families. *Journal of Pediatric Psychology*, 37, 424–437.
- Landolt M, Buehlmann C, Maag T, Schiestl C (2009). Quality of life is impaired in pediatric burn survivors with posttraumatic stress disorder. *Journal of Pediatric Psychology*, 34, 14–21.
- Luthar SS, Cicchetti D, Becker B (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child Dev*;71(3):543-562.
- Masten AS (2001). Ordinary magic: Resilience processes in development. *American Psychologist*, 56, 227–238.
- Mock SE & Arai SM (2011). Childhood trauma and chronic illness in adulthood: Mental health and socioeconomic status as explanatory factors and buffers. *Front Psychol*;31:1:246
- Monti JD, Winning A, Watson KH, Williams EK, Gerhardt CA, Compas BE, Vanatta K (2017). Maternal and paternal influences on children's coping with cancer-related stress. *J Child Fam Stud*.26:2016-2025.
- Nabors LA, Yockey A, Merianos AL, Hardee A (2016). Resilience in children with chronic illnesses and



### 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](http://www.nhpco.org/pediatrics)

- their families. In LV Berhardt (Ed.), *Advances in Biology and Medicine*, Edition: 104, Chapter: 4, Publisher: NOVA.
- Resilience (n.d.) In *Merriam-Webster's Online Dictionary*. Retrieved March 18, 2018, from <http://www.merriam-webster.com/dictionary/resilient>.
- Resilience (n.d.) In Center on the Developing Child at Harvard University. Retrieved March 21, 2018 from <https://developingchild.harvard.edu/science/key-concepts/resilience/>.
- Roder I & Boekaerts M (1999). Stress, coping, and adjustment in children with a chronic disease: A review of the literature. *Disability and Rehabilitation*, 21(7), 311-337.
- Rolland JS & Walsh F (2006). Facilitating family resilience with childhood illness and disability. *Current Opinion in Pediatrics*, 18(5), 527-538.
- Rutter M (1979). Protective factors in children's responses to stress and disadvantage. In: Kent, MW, Rolf J (Eds.). *Primary Prevention of Psychopathology Volume III: Social Competence in Children*. Hanover, NH: University Press of New England; p. 49-74.
- Rutter M (2006). Implications of resilience concepts for scientific understanding. *Ann NY Acad Sci.*;1094:1–12.
- Sawyer SM, Drew S, Yeo MS, Britto MT (2007). Adolescents with a chronic condition: Challenges living, challenges treating. *Lancet*, 369, 1481-1489.
- Shapiro ER (2013). Nurturing family resilience in response to chronic illness: An integrative approach to health and growth promotion. In D. S. Becvar (Ed.). *Handbook of Family Resilience* (pp. 385-408). New York: Springer.
- Skinner EA, Edge K, Altman J, & Sherwood H (2003). Searching for the structure of coping: A review and critique of category systems for classifying ways of coping. *Psychological Bulletin*, 129(2,) 216-269.
- Skinner EA, Zimmer-Gembeck JJ (2007). The development of coping. *Annual Review of Psychology*, 58(1), 119–144.
- Smith J, Cheater F & Bekker H (2015). Parents' experiences of living with a child with a long-term condition: A rapid structured review of the literature. *Health Expectations*, 18(4), 452-474.
- Stewart M, Reid G, Mangham C (1997). Fostering children's resilience. *Journal of Pediatric Nursing*, 12, 21–31.
- Stuber ML, Schneider S, Kassam-Adams N, Kazak AE, Saxe G (2006). The medical traumatic stress toolkit. *CNS Spectrums*;11:137–142.
- Turkel S & Pao M (2007). Late consequences of pediatric chronic illness. *Psychiatr Clin North Am*; 30(4): 819–835.
- Wallander JL, Varni JW, Babani L, DeHaan CB, Thompson Wilcox K, Tweddle Bannis H (1989). The social environment and the adaptation of mothers of physically handicapped children. *Journal of Pediatric Psychology*, 14, 371–387.
- Walsh F (2012). Family resilience: Strengths forged through adversity. *Normal Family Processes*, 4, 399-427.
- Werner EE, Smith, RS (1982). *Vulnerable but Invincible: A Longitudinal Study of Resilient Children and Youth*. New York: McGraw-Hill.
- Wolchik S, & Sandler IN (Eds.). (2013). *Handbook of Children's Coping: Linking Theory and Intervention*. Springer Science & Business Media.
- Yi-Frazier JP, Yaptangco M, Semana S, Buscaino E, Thompson V, Cochrane K, Tabile M, Alving E, Rosenberg AR (2015). The association of personal resilience with stress, coping, and diabetes outcomes in adolescents with type 1 diabetes: Variable- and person-focused approaches. *Journal of Health Psychology*, 20, 1196–1206.

###



### 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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

## CONSIDERING CAREGIVER BEREAVEMENT

### WITHIN THE CONTEXT OF AN ADOLESCENT SUICIDE ATTEMPT

**Pamela Orren, PhD**  
 Clinical Psychologist  
 Kaiser Permanente Northern California  
[Pamela.Orren@kp.org](mailto:Pamela.Orren@kp.org)

A topic that is not often associated with traditional bereavement is that of the grief process for caregivers following an adolescent suicide attempt. Recent data from the Center for Disease Control (CDC, 2015) indicates that suicide is now the third leading cause of death among individuals between the ages of 10 and 14 and the second leading cause of death among individuals between the ages of 15 and 34 (NIMH, 2017). The American Foundation for Suicide Prevention (AFSP, 2018) postulates that for every completed suicide attempt, there are 25 suicide attempts. Additional research indicates that adolescents are within a high risk category for suicide attempts (NIMH, 2017).

The bereavement process for the friends and families of the identified patient is varied. Themes of shame, guilt, and even anger are quite common. This article will address common themes of bereavement for a broadly-defined category of caregivers—which may include both family members and friends. Guidance regarding coping skills and support will also be addressed. While the research shows that suicide attempts amongst children ages 10-14 is dramatically on the rise and needs to be addressed, this article will focus on suicide attempts amongst the adolescent (12-17) population.

Providing medical care to hospitalized pediatric patients can often be challenging and emotionally overwhelming. A recent study reviewed acute stress responses and symptoms of post-traumatic stress disorder among healthcare professionals who care for injured and critically unwell patients and concluded that there is a “hidden, untreated burden” of stress symptoms among frontline healthcare providers (Naumann et al., 2017). This article will address care of parents or guardians after an adolescent suicide attempt. However, there are many other individuals, such as medical professionals or teachers (particularly if they are parents themselves) who warrant extra care and attention as they too navigate through this process.

The process of caregiver stress and bereavement after a suicide attempt often begins earlier when a patient is brought to an Emergency Department or admitted to a hospital for medical care. It typically begins when an adolescent indicates to a friend or caregiver that he or she has made an attempt to end his or her life. Initial feelings of fear and panic are common while awaiting medical attention. Once medical treatment has been obtained, sentiments of anger, frustration, and blame are common responses from caregivers. Caregivers often report feeling as if they were “on autopilot” or that the process of learning about the attempt and obtaining initial medical care was “surreal.” These initial and almost universal emotional reactions from caregivers are likely indicators of acute stress. During this acute phase, it is crucial to provide information regarding the patient’s medical status to the caregiver and to offer additional emotional support. The stigma of mental health care, and particularly of suicide attempts, often precludes caregivers from contacting their own support systems at the time of acute stress. However caregivers should be encouraged to seek their own support systems as they provide care for their child.

Approaching an adolescent following a suicide attempt may be exceedingly difficult for all caregivers. Engagement with the child or adolescent patient can prove challenging, as these patients often suffer from a depressive process and may struggle with social engagement. During interactions with the adolescent, it is critical to not portray a sense of judgment or blame. Patients often describe feeling “embarrassed” or “shameful” following a suicide attempt and the goal is to offer support and comfort. A sense of hopelessness is often pervasive within patients post suicide attempt. One can normalize the



#### **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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

sentiments of shame and hopelessness, but the true work for the treating medical team and the caregiver lies in comprehending the underlying emotions that led the patient to attempt suicide. Some caregivers are quick to engage patients in conversations or activities to “cheer them up.” This should be avoided, as patients have previously described these well-intended attempts at engagement as belittling or minimizing of their experience. Diligence should be paid to joining these patients where they are in the process and for mirroring their emotions.

It is within this phase of the treatment trajectory that caregivers often describe their own conscious experience with bereavement. Emotional processes such as sorrow, shame, guilt, and anger amongst caregivers is common and can best be understood within the context of bereavement. These emotional states are not universal, nor do they tend to follow a linear pattern for caregivers—many may experience one emotional state only to find themselves at that same state days or weeks later. Reflection on who the child was when they were younger or favorite memories of the adolescent often produce a sense of comfort, though extreme sadness regarding the perceived “loss” of that individual may occur. The shame that is associated with an adolescent suicide attempt may paralyze parents from disclosing the event to their own loved ones, rendering the caregiver without a support system. Caregivers often quickly blame themselves for not being able to stop the suicide attempt or for not “paying enough attention” to the child. Anger is also frequently experienced by parents and, at times, engagement between the child and parent during medical hospitalization may be contraindicated. A unique, yet prevailing, paradigm that exists occurs when caregivers attempt to shield the child from their own emotional reactions and experiences—fearing infliction of additional stress upon the adolescent.

It is essential that caregivers are provided with the physical and emotional space to cope with their own reactions to an adolescent suicide attempt. The subtle messages that caregivers receive throughout the immediate aftermath of a suicide attempt are typically misinterpreted. Caregivers may interpret and internalize thoughts such as “I need to be strong” or “I can’t let my child see how much I am hurting right now.” Caregivers must be encouraged by others to express their own emotions and to engage in their own adaptive manners of coping. Frequent breaks from the hospital setting are encouraged. Many find that a return to their typical routine brings not only predictability and consistency but also a sense of content. Increased interpersonal social support and even more traditional mental health care services may lead to improved late outcomes in regards to overall caregiver physical and mental health.

**TABLE 1: Guidelines for Caregivers following an adolescent suicide attempt**

<b>Acute Phase:</b>	<b>Treatment Phase:</b>	<b>Stabilization Phase:</b>
Seek information about the patient’s ongoing medical status.	Provide ongoing support to patient free of judgment or blame.	Work with patient to increase communication and plans to ensure safety.
Explore own support systems and family/friends.	Attempt to comprehend the underlying emotional states of the patient that led to suicide attempt.	Engage in ongoing mental health care.
Evaluate and engage in healthy, adaptive coping skills.	Prioritize self-care.	Continued self-care and engagement in coping skills.

The experience of being a caregiver for an adolescent following a suicide attempt is often harrowing and ambiguous. The bereavement process does not end when the patient medically stabilizes; in fact, it often continues for years as both the patient and their caregiver enter into longer-term mental health treatment. Normative bereavement following a suicide attempt remains unclear and varied. However, outcomes will likely be improved with increased normalization and validation of the bereavement trajectory for both adolescent patients and their caregivers.

#### References:

American Foundation for Suicide Prevention. (2018, February). *About Suicide*. <https://afsp.org/>



#### 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](http://www.nhpco.org/pediatrics)

Center for Disease Control. (2015). Suicide: Facts at a Glance.  
<https://www.cdc.gov/violenceprevention/pdf/icide-datasheet-a.pdf>

National Institute of Mental Health. (2017, March). *Suicide Prevention*.  
<https://www.nimh.nih.gov/health/topics/suicide-prevention/index.shtml>

Naumann, D.N., McLaughlin, A., Thompson, C.V., Hardy, E., Fellows, J.L., & Crombie, N.C. (2017). Acute stress and frontline healthcare professionals. *Journal of Paramedic Practice*, 9(12), 516-521.  
<https://doi.org/10.12968/jpar.2017.9.12.516>

-###-



**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](http://www.nhpco.org/pediatrics)

## HOW HONESTY HEALS A COMMUNITY CRISIS

**Rebecca Konarz, LMSW, IMH-E**

Willow of Wonder Child and Family Therapy PLLC

[konarz5@att.net](mailto:konarz5@att.net)

In the face of tragedy, especially an unforeseen or sudden death of a child, the first response of parents and adult caregivers is to shield their own child, or the other children in the community, from the situation. However, the best antidote to surviving community tragedy is honesty; both for you, as the parent or caregiver, and for the community of children involved. Honesty is difficult amidst crisis, but the following guidelines should assist a community in changing a tragedy into a moment of solidarity and support, especially when there has been a child or teen that has died.

In 2018, *Merriam-Webster Dictionary* defines community as *a unified body of individuals*. Unification is an important goal following community calamity, beginning with the family of the child who has died. While social media has taken on the role of making life-changing announcements to the world, help keep the information localized and at the discretion of the family. Find a point person for the family, or a close friend with whom the family has entrusted, for communicating information surrounding the death, as well as for meeting the needs of the family.

Once the family has made a statement, or appropriate information has been announced from a reliable source, community members can begin sharing the news with their own families. As an adult, ask yourself what emotions have surged inside of you upon hearing this news; how has this impacted your view of your own children or grandchildren; how may this affect your child positively or negatively; and what is the most important aspect of your coping you want to share with your child.

A father once shared tearfully, “While I never knew this little boy, nor did our son, they both had blonde hair, they loved trains and baseball, and they loved the Detroit Tigers.” These similarities of our children to the deceased can cause an outburst of emotion in us, as parents and caregivers. These intense emotions may be both a surprise to the adult, and may even be so intense and out of character, that the intense emotions alone can cause a young child to be distraught. While sharing your emotions daily with your child is best, sometimes amid crisis, adults need to process with other adults or spouses, ask themselves the above questions, and then formulate a support team and plan to begin engaging their children in a conversation regarding the death. Being honest with ourselves, whole-heartedly, and processing it accordingly, will make the conversation with our children sincere.

Most can vouch that a main goal in parenting, which is instinctual in nature, is to protect our sons and daughters, but the most important lessons in life are learned through personal experience. This leads us to the most difficult part of a child’s death—sharing this death with the innocent heart of our own child. This task is emotionally exhausting, yet it builds a true sense of safety between a child and parent, as well as an everlasting trust. In having prepared this conversation in advance, you will build your confidence to broach the subject justly. Give your child the basic information; cause of death if known, any circumstances leading up to the death (i.e., chronic illness, unsafe living environment, mental illness, etc.), and how it directly affects your family. You can end by asking if your child needs more information, needs time to process the information shared, or has any questions. Young children typically honestly ask if they have questions, while older children and teenagers may seek the comfort of their older siblings or peers.

In more sudden or tragic deaths, sometimes honesty means using discernment within your own family belief system. For example, if the death was by suicide, yet the family does not want this information shared publically, your judgement as a parent is then at the forefront. Professionally, it is in the best interest of your child to hear this devastating news from you, in a protected environment, rather than at school. Children who were not privy to the truth from their parents may internalize the death and create their own ending to the story, which may or may not include falsifying information. In the case of a



**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](http://www.nhpco.org/pediatrics)

homicide, it is important to mention that the child died from being very, very, very seriously hurt caused by a person who was not able to make healthy, safe choices. You know your child best, and you know their peers, so every parent has to decide what is best for their child's needs. At the end of the storm, truth does prevail many times. Your integrity creates a moral compass. Honesty builds trust, and trust builds strong relationship bonds, another important mission of parenting.

In terms of deepening these conversations and opening the doors of communication with your child, here are three engaging statements that can be used with a child of any age in the midst of a family crisis: (1) Tell me your biggest worry since this has happened; (2) Help me understand what you need from me or other adults right now; (3) Draw or write the hardest part of this journey. These statements provide opportunity for genuine, albeit difficult, conversations with your child. While each child's temperament is unique, young children deserve to know as well. They may have nothing to add, yet I know many four year olds that have offered candid wisdom to healing adults. Lastly, it is important to remember that as parents and caregivers, we will not always know why, and it is perfectly healthy to tell your child, "I cannot tell you why this happened; we do not know the answer, but I can assure you we will do everything we can to support you and help you through this."

As a school professional, use your discretion at reaching out to the family of the deceased child. School environments are vastly different from district to district. Some districts have policies in place, while others seek out the family directly in a home visit. In either case, be sure to connect with the family point person who can ensure that the best interests of the family and siblings are at the forefront. As the parent of the deceased, some families have written a statement regarding the death, including the type of death, surrounding circumstances, and the need for privacy. Again, while social media has created a space for delivery of news, always leave this to the discretion of the family. Only they will know what is in their family's best interest.

Furthermore, adequate support for the school staff is absolutely necessary to meet the entire school community's needs. From the custodian to the principal, no one can determine the role a school staff member may have played in the life of the child who died and no staff should be excluded. Teachers, who are willing and able, should encourage their students who were peers to the deceased child to write cards of hope, a funny memory of how the deceased child made the student laugh, or short stories about something kind the deceased child did for them. Be sure a school staff reads over these cards for appropriateness prior to handing them over to the family.

By being authentic with our children in face of calamity, trust between a child and parent/caregiver grows and thrives. Honesty is difficult in these tragedies, but at the end of life's most challenging journeys, unity and honesty will almost always calm even the harshest storms.



### **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](http://www.nhpco.org/pediatrics)



## CRISIS AND HEALTH CARE WORKERS: WHAT WE SHOULD CONSIDER

**Anna Konstantin, MSN, CNL**  
 UCSF Benioff Children's Hospital Oakland  
 Oakland, CA  
[akonstantin@mail.cho.org](mailto:akonstantin@mail.cho.org)

I recently read an article on how to deal with crisis called, "Coping with Crisis: Five Tips for Looking after Yourself in the Aftermath of Adversity" (Joseph, 2013). It discussed all the things that could be considered a crisis. The definition was broad enough that you could conclude a crisis is anything that causes a major negative disruption of your life, including but not limited to the death of a loved one, divorce, an accident or disaster, or the diagnosis of an illness. The article gave great advice on how to handle overwhelming feelings. First, make sure you are physically safe; if you are not, get to a safe place. Next, call for help or get the help you need (this may be medical, legal, or psychological). Next, plan physical activity. Finally, make sure you are eating well and getting plenty of sleep: many times during a traumatic event or time in our life we forget to take care of our basics.

The article eloquently points this out and offers great advice, but it got me thinking: I know many nurses and health care professionals who are over- or underweight, who frequently go without sleep, who do not exercise or plan any time for physical activity, who have their own health issues that they aren't taking care of, and who work in unsafe conditions. I work and have worked in a pediatric intensive care unit for 11 years as a bedside nurse. I have seen more trauma than I can recall. I have watched parents hold their babies while they take their last breath. I have held a child while he has taken his last breath. I have held the hand of a teenager who was beaten and sodomized. Yet I leave work and head home or to the grocery store as if I had spent the day balancing an accounting sheet. But the next day, I can't seem to find the energy to get out of bed. I open a bag of chips because making lunch just seems too difficult. I tell myself I just need some sleep, but 12 hours in bed asleep give me no relief. I only work four days a week; why am I so tired? Why can't I muster the energy to attend my sister's birthday party? Why does paying my bills feel so overwhelming? What is wrong with me?

It finally dawned on me that although the child who died wasn't mine, the trauma is. Working in a traumatic environment and watching those around you go through unbelievable and occasionally nonsurvivable trauma is traumatic. Yes, it is a job, but I am human. My feelings, my body, and my soul are changed in unmeasurable ways.

Many health care workers must not realize the trauma they themselves are experiencing. It is obvious in how little we take care of ourselves. The five basic items listed above were the focus of Joseph's article, but these seemingly simple things are frequently overlooked by health care providers. We push our feelings aside. We eat our feelings. We lay on the couch for hours attempting to disconnect from our minds by binge-watching Netflix. We ignore our bills, our families, our lives. I'm just tired from work, I say. It's just a cold, I say. I'll make my doctor's appointment next week, I say. Instead, I find myself angry at work, angry at home, angry at my husband, and angry at my kids. I quit my job, I move to a different unit, and I'm still angry, still unhappy, and still restless. I can't lose weight or pay the bills. I cry when I burn dinner, I yell when I'm stuck in traffic. I can't remember the last time I took a deep breath or didn't pass out on the couch from exhaustion.

But what if things could be different? What if I tried to take care of myself as if it was my traumatic event? What if first I made sure I worked in a safe environment and went home to a safe place? Next, I could make and keep the appointment with my doctor, the appointment with my tax guy, and the appointment with my therapist. What if I planned a weekly walk with friends and didn't cancel, or took the stairs instead of the elevator? Can I take the time to plan healthy meals and snacks or recruit help to do this? Can I journal before bed and actually fall asleep peacefully, not on the couch as I binge-watch Netflix? Instead of burning out in 10 years, can I take care of myself so that I may take care of those who need me?



### 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](http://www.nhpco.org/pediatrics)

I don't think the answer is yes for everyone. Nurses burn out at a dramatically high rate. According to Vahey, Aiken, Sloan, Clarke, and Vargas (2004), more than one-third of nurses intended to leave their positions within the next year. According to Zimmerman (2017), 7 out of 10 nurses burn out of their jobs. Many factors have been cited in articles relating to burnout; therefore, I cannot conclude that every person can and will stay in the health care field and remain healthy mentally, physically, and emotionally. I do know if we do not start recognizing the trauma we are going through and begin treating that trauma, we will not stay in the field and we will not stay healthy, causing those who need us most (our patients and families) to suffer.

## References

- Joseph, S. (2013). Coping with crisis: Five tips for looking after yourself in the aftermath of adversity. *Psychology Today*. Retrieved from <https://www.psychologytoday.com/us/blog/what-doesnt-kill-us/201301/coping-crisis>
- Vahey, D., Aiken, L., Sloan, D., Clarke, S., & Vargas, D. (2004). Nurse burnout and patient satisfaction. *Medical Care*, 42(2), 1157–1166. doi:10.1097/01.mlr.0000109126.50398.5a
- Zimmerman, B. (2017). Survey: 70% of nurses report burnout in current position. *Becker's Hospital Review*. Retrieved from <https://www.beckershospitalreview.com/human-capital-and-risk/survey-70-of-nurses-report-burnout-in-current-position.html>



### 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](http://www.nhpco.org/pediatrics)

## THINKING ABOUT HELPING WHEN TRAUMATIC EVENTS OCCUR

**Patti Anewalt, PhD, LPC, FT**

Director, Pathways Center for Grief & Loss  
Hospice & Community Care  
Lancaster, PA

[panewalt@hospicecommunity.org](mailto:panewalt@hospicecommunity.org)

[www.pathwaysthroughgrief.org](http://www.pathwaysthroughgrief.org)

### Jumping into Traumatic Events: A Caution

The fall of 2017 saw an unprecedented number of community disasters between hurricanes, wildfires, and the Las Vegas shooting. This caused many who work in hospice and palliative care to wonder how they would, or should, respond if a traumatic event occurred in their community. Yet just because pediatric hospice and palliative care professionals work with dying children and their family members, does not mean they have the training, experience, or skill set to help in situations such as suicides or mass casualties in community tragedies. One actually has very little to do with the other.

Traumatic sights, sounds, and experiences are an inherent part of community tragedies. Working with the community, as well as with the first responders who are frequently exposed to these traumatic experiences, takes specific training and experience. This is why, after the Las Vegas shooting in October 2017, when the Association for Death Education & Counseling put out a Call to Action, it specified the need was for licensed therapists with 5 or more years of experience with violent traumatic death.

As tragic and difficult as it is to be present with a family whose child is dying of cancer, for example, that involves a natural death. This is what pediatric hospice and palliative care staff helps families face regularly. Losing a child in a school shooting, a school bus accident, or a terrorist incident is very different because someone else caused their child to die. There may be aspects that could have been done differently that might have changed the outcome, details are far more public rather than private, many more people are affected, and the trajectory for healing can be even longer than it is for a parent whose child died from a natural death.

### Managing Priorities

Another consideration is the fact that the first priority in all pediatric hospice and palliative programs is managing the needs of the patients and families they serve. When a community tragedy occurs, if some staff *were to* reach out and offer assistance by responding on scene, this means they would not be available to meet the needs of the patients and families they had been serving. And in many cases with community tragedy, if you do respond, you may continue to be needed beyond the initial engagement. Do you have that kind of availability and back up? Many hospice and palliative care programs do not have that kind of staffing flexibility.

Another fact to be aware of is that when a community tragedy occurs, there is so much media attention on the situation that patients and families who are currently enrolled in pediatric hospice or palliative care programs and who *do* have needs can feel disenfranchised and be apologetic when they express their needs. So hospice and palliative care professionals need to be particularly sensitive to this possibility at times of community tragedy. By paying close attention to the needs of parents and family members who are currently enrolled in their programs, care providers can reassure the patients and families whom they serve that their needs continue to be their priority. They can ensure that those needs are just as important as they always were and continue to be so.

### Anticipating Involvements

Hospice and palliative care programs that want to play a role when community tragedies occur need to



#### 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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

prepare for such involvements by developing relationships with the local stakeholders that are already actively involved in community crises. The American Red Cross, Emergency Management and Critical Incident Stress Management (CISM) Teams, Disaster Crisis Outreach & Referral Teams (DCORT), Victims' Advocates, Medical Reserve Corps (MRC), The Salvation Army, and local hospitals are some of the organizations to develop relationships with. All of these are already existing organizations with teams of individuals who are trained and respond regularly to community crises. They are the first ones to be involved or to appear on the scene, in addition to dispatch and fire, police, and emergency responders.

In Las Vegas after the shootings in October 2017, Nathan Adelson Hospice's chaplain department reached out to one of the local hospitals who were overloaded with patients. They offered to provide some coverage for a few days because the hospital's chaplains worked overtime in the days that followed the shooting. In so doing, they offer an example where collaboration worked well because the hospice already had a good working relationship with the local hospital. On the other hand, in Chattanooga Tennessee in 2016 there was a horrific school bus accident where six children died and 23 were hospitalized with six in critical condition. The local Red Cross Disaster Mental Health Team coordinated the crisis response and although a local counseling agency also responded on scene, those counselors were frustrated to find they weren't needed because of the Red Cross involvement. As a result of that, going forward, those local counselors started meeting monthly with the Red Cross. Their hope was to better understand the Red Cross system with the goal of improved collaboration in the future.

### How Best to Help

Another aspect for pediatric hospice and palliative care professionals to consider is where they might be most needed. When a local tragedy occurs, many tend to think of the immediate response on the day of the crisis. In reality, the mental health fallout from community tragedies only becomes evident in the weeks that follow the actual incident. Providing some education in the form of written materials or local TV spots, for example, about grief, loss and trauma, might be something you as a hospice and palliative care provider could offer. This could be in collaboration with the other organizations that are active in your community who are offering education and support in the weeks that follow after a community tragedy.

Perhaps you already offer grief support groups for parents in your program or in the community who are grieving the death of a child. If so, you might consider adding a group specifically for the parents and family members who had a child die in a situation like a mass casualty resulting from a school shooting in your community. Of course, it would be important to consider when it would be best to offer such a service. Very likely, given the horrific circumstances and public nature of the incident, parents and other family members would not be ready to engage with your services for months, not weeks, after the tragic event.

### Conclusion

What is most important for pediatric hospice and palliative care professionals who are thinking about helping when traumatic events occur is to look at what the needs are in each situation, as well what their expertise, experience, and availability is, to determine where the best fit will be.

-###-



#### 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](http://www.nhpco.org/pediatrics)

## RESOURCES FOR PROVIDING SUPPORT FOR CHILDREN AND FAMILIES

### EXPERIENCING OR GRIEVING FROM CRISIS OR TRAUMA

Compiled by Ann Fitzsimons, BS, MBA

Executive Director of here4U, Inc.

[Ann@here4U.net](mailto:Ann@here4U.net)

The following websites are offered as additional resources to help professionals who find themselves in a position to care for a child or family, who is experiencing or has experienced some type of crisis or trauma—from a suicide of a loved one or peer, to a school shooting, to a natural disaster, to some other type of personal crisis or trauma in a family. To some families, this could include caring for, and living with, a child who has a life-threatening illness. While some of these resources are geared more to school teachers/administrators, the supportive care advice offered has relevance for professionals and families practicing and living in the hospice and palliative care world.

#### **CRISIS HOTLINE NUMBERS**

National Suicide Prevention Lifeline	1-800-273-8255
Suicide Hotline	1-800-Suicide
Depression & Crisis Hotline	1-800-784-2433
The National Institute for Trauma and Loss in Children	1-877-306-5256
Families Anonymous (Addiction/Recovery)	1-800-736-9805
Al-Anon Family Groups (Addiction/Recovery)	1-888-425-2666
Post Partum Depression	1-800-944-4773

#### **SCHOOL-RELATED CRISES/TRAUMA/GRIEF**

##### **Coalition to Support Grieving Students (<https://grievingstudents.org/>)**

This Coalition is a collaboration of some of the leading professional organizations in school education and administration whose purpose it is to create and share a set of industry-endorsed resources that will empower American school communities in the ongoing support of grieving students.

Their website provides video and downloadable grief support modules for school personnel on topics like:

- Talking with Grieving Children
- Providing Support Over Time
- Peer Support of Grieving Children
- Developmental & Cultural Considerations of Grieving/Bereaved Families
- Practical Considerations
- Reactions and Triggers
- Professional Preparation & Self-Care
- Crisis and Special Circumstances (e.g., death in a school community, suicide, commemoration and memorialization, and support for students with life-limiting conditions)

The website also has a Compendium of mini articles on these topics at the following link:

<https://grievingstudents.org/wp-content/uploads/2016/11/mini-articles.pdf>

##### **National Center for School Crisis and Bereavement ([www.schoolcrisiscenter.org](http://www.schoolcrisiscenter.org))**

The NCSCB offers free educational materials for school professionals and communities preparing for or responding to crisis events. They also offer expert consultation and training, as well as the following



#### **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](http://www.nhpco.org/pediatrics)

resources/guides, many which can be downloaded from their website:

- Guide: Grief Over the Holidays
- Guide: Student Commemoration
  - Recommended guidelines for schools on commemoration of students at graduation
- Book: How to Prepare for and Respond to a Crisis
- Book: The Grieving Student: A Teacher's Guide
- Teacher Training Modules geared toward school professionals supporting grieving students
- Line-of-Duty Deaths: Police & Military
  - Provides guidelines for supporting children and family survivors of line-of-duty deaths
- Clinical Guidelines: Bereavement
  - A clinical report offering practical suggestions for pediatricians and other child healthcare providers on how to support grieving children and families
- Clinical Guidelines: Support After Disaster
  - A clinical report offering practical suggestions on how to talk with grieving children about disaster to help them better understand what has happened
- Guidelines for Schools Responding to a Death by Suicide
  - Guidelines designed to help school administrators, teachers, and crisis team members respond to the needs of students and staff after a suicide has impacted the school environment, as well as when an individual student's life may be impacted by a suicide within the family
- Psychological First Aid for Children, Parents, and Other Caregivers After Natural Disasters
  - This Guide provides practical advice for parents and other caregivers on the three steps of psychological first aid to help children cope with natural disasters

To speak to one of their experts (if you are a school or other organization), contact them at: [prepare@scoolcrisiscdnter.org](mailto:prepare@scoolcrisiscdnter.org) or call 1-877-536-2722.

### **SUICIDE-RELATED CRISES/TRAUMA/GRIEF**

#### **American Association of Suicidology ([www.suicidology.org](http://www.suicidology.org))**

The American Association of Suicidology offers a variety of resources and programs to survivors in an attempt to lessen their pain as they grieve the loss of someone to suicide. These include:

- A Survivors Info Kit
- A booklet and handbook on coping from a suicide loss
- A Resource Catalog of books, pamphlets, etc. for children and those who care for them
- A Directory of Survivors of Suicide Support Groups

Resources are available for those individuals who attempt suicide, clinician survivors, and loss survivors.

#### **American Foundation for Suicide Prevention ([www.afsp.org](http://www.afsp.org))**

This is a voluntary health organization whose mission it is to try to save lives and bring hope to those affected by suicide. This is done by funding scientific research on the topic, educating the public about mental health and suicide prevention, advocating for public policies in mental health and suicide prevention, and supporting survivors of suicide loss and those affected by suicide. This organization has local chapters in all 50 states and also sponsors national programs and events.

Website support is organized by these categories:

- I've lost someone
- I'm worried someone might be at risk
- I've made an attempt



#### **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](http://www.nhpco.org/pediatrics)

- My loved one has made an attempt

This organization also conducts a Facilitator Training Program which offers suicide prevention organizers a way to create and facilitate a community support group for suicide loss survivors in the aftermath of a suicide. One of the training sessions is to teach facilitation of a Suicide Bereavement Support Group for Children and Teens.

### **Survivors of Suicide ([www.survivorsof suicide.com](http://www.survivorsof suicide.com))**

This is a website established to help those who have lost a loved one to suicide find resources to help them resolve their grief and pain in their own, unique way. It includes a Circle of support, Tips to Help a Survivor Heal, FAQ's about suicide, and a Directory of support groups, among others.

### **The Trevor Project (<https://www.thetrevorproject.org>)**

This is the leading national organization providing crisis intervention and suicide prevention services to lesbian, gay, bisexual, transgender, and questioning young people aged 13-24.

The website has sections on Getting Help, Education, and Resources, and includes:

- A Lifeguard Workshop, which is a free online learning module for teachers in middle and high school classrooms
- Trainings for Professionals which include trainings designed for adults who work with youth. These trainings are designed to help counselors, educators, administrators, school nurses, and social workers discuss LGBTQ-competent suicide prevention.

The site also has specific resources for youth on how to take care of themselves and how to help a friend who may be struggling with suicidal thoughts.

This organization also offers a 24/7 crisis line for a young person who may be feeling suicidal and/or in need of a safe and judgement free place to talk with a counselor. The Trevor Lifeline is: 866-488-7386.

### **DISASTER-RELATED CRISES/TRAUMA/GRIEF**

#### **American Academy of Pediatrics (<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Children-and-Disasters/Pages/default.aspx>)**

The American Academy of Pediatrics hosts several resources and links for pediatricians/other doctors who care for children to reference/use in preparation for, during, or after disasters. These include:

- Information on treating/caring for children and youth with special needs during an emergency situation
- Family Readiness Kit
  - Downloadable document to assist families to prepare for disasters
- Disaster Preparedness in NICUs
  - Guidelines to help doctors develop disaster response plans within their units, hospitals, and regions
- Ensuring Child Health in Disasters
  - Pediatricians role in preparing and treating families in cases of disasters
- Providing Psychosocial Support
  - An AAP Clinical Report titled Providing Psychosocial Support to Children and Families in the Aftermath of Disasters and Crises
- Infant Feeding in Disasters
  - Steps pediatricians can take to support breastfeeding during a disaster or emergency
- Youngest Victims



#### **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](http://www.nhpco.org/pediatrics)

- Disaster preparedness to meet children's needs
- Helping Children Cope
  - Details on how adults can promote adjustment and help children cope in a disaster
- Among others

**American Red Cross Disaster Preparedness Training (<https://www.redcross.org/take-a-class/disaster-training>)**

The American Red Cross offers online training modules on the following topics:

- Disaster Mental Health: Introduction for individuals interested in becoming a Red Cross Disaster Mental Health responder
- Disaster Health and Sheltering for Nursing Students designed to introduce nursing students to the role of health and functional support needs in Red Cross Disaster Shelters

This website outlines ways individuals can serve their community before/during/after disasters including:

- Joining a Local Disaster Action Team
- Teaching/Educating about Preparedness to individuals/groups
- Becoming a Disaster Mental Health Volunteer
- Teaching Courses to Medical/Public Safety professionals on disaster preparedness

The American Red Cross also offers training in the Fundamentals in Disaster Spiritual Care.

**Experiencing Grief in College (<https://www.accreditedschoolsonline.org/resources/managing-grief/>)**

This site provides expert advice on recognizing symptoms of grief, accepting loss, and getting help when it's a college student who is away at school. The site touches on the topics of taking care of themselves, identifying symptoms of grief, and knowing when and where to seek help.

**National Institute for Trauma and Loss in Children (<https://www.starr.org/training/tlc>)**

This Institute's mission is to provide services to traumatized children and their families. They also work to give school professionals, crisis intervention teams, medical and mental health professionals, childcare professionals, and others the training and resources needed to help children, parents, families, and schools thrive. They do this by equipping professionals with the right tools for trauma counseling by providing online training courses, resources/materials, and conferences to therapists and other professionals and caregivers to help guide children, adults, families, and communities through the devastating effects of trauma. The website includes downloadable resources as well as an online store for books, interventions, and more.

**The Centering Corporation (<https://centering.org/>)**

The Centering Corporation is a non-profit dedicated to providing education and resources for the bereaved. This includes Children and Teen Grief Resources for when friends die, for school deaths, and when unexpected traumas/crisises/accidents happen. They also have a section of books and resources on Suicide, Homicide, Drug Overdose and Trauma Resources for children and adults.

It is important to note that in the last 10 years, Centering Corporation has donated free books to 30 regional and national tragedies, with 2,000 books being donated in the last 18 months via [www.freegriefbooks.org](http://www.freegriefbooks.org).

**National Organization of the Parents of Murdered Children, Inc. (<http://www.pomc.com/>)**



**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](http://www.nhpco.org/pediatrics)



The mission of this organization is to provide support and assistance to all survivors of homicide victims via ongoing emotional support, education, prevention, advocacy, and awareness.

POMC has state/local chapters which hold monthly meetings to provide support, advocacy, and court accompaniment to these parents. The website also hosts an Ask the Experts<sup>SM</sup> service where people can ask legal experts non-case specific questions.

### **Scholastic Children and Grief Guidance and Support Resources**

**(<http://www.scholastic.com/childrenandgrief/>)**

This website includes resources for families and teachers. Family resources include downloadable guides on Children and Loss as well as Bereavement Camp information.

Resources for Teachers include:

- About Children and Grief
- How Teachers Can Help
- Loss and the School Community

### **The LLost Foundation (Loss of Loved Ones to Sudden Tragedy) (<http://llost.org/>)**

This organization was created to provide support to those who are living with the loss of a loved one to sudden tragedy. It helps provide funeral expenses for families in need, as well as offers online support via a private Facebook page and links to books/resources for many types of death, including from homicide, suicide, and of someone in law enforcement or the armed forces.

### **The Moyer Foundation (<https://moyerfoundation.org/resources/>)**

The mission of the Moyer Foundation is to provide comfort, hope, and healing to children and families affected by grief and addiction. Their resources and programs aid to address the needs of children experiencing all that comes with the death of someone close to them or by having substance abuse present in their families. Their resources include those for families, school communities, and the general population on topics like:

- Building resilience skills to help deal with loss and grief
- Trauma and grief center guidelines for parents/caregivers for helping bereaved youth
- Guidelines for responding the death of a student or school staff (for teachers/administrators)
- Information on how teachers and schools can help when “bad stuff” happens, among others, among others

### **The Sudden Unexplained Death in Childhood (SUDC) Foundation (<https://sudc.org>)**

This Foundation is dedicated to increasing the awareness of sudden unexpected deaths in childhood, and funding crucial research to better understand and prevent these tragedies. They aim to support and meet the needs of both families and professionals touched by unexpected/unexplained deaths in children. Their services are provided at no cost to the families, and include:

- Individualized case advocacy with navigating the death investigation process
- Personalized support by licensed clinical social workers
- Unique private web-based support groups
- Peer support programs matching trained family volunteers with newly bereaved
- Resources for siblings and grandparents
- Memorial and event planning websites
- DNA banking services
- Research opportunities
- Private access to a Family Directory



#### **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](http://www.nhpco.org/pediatrics)

**Tragedy Assistance Programs for Survivors (<https://www.taps.org/>)**

This program offers compassionate care resources to all those grieving the loss of a military loved one, including:

- Survivor Care Team
- Grief Counseling
- Casework
- Suicide Loss Survivor

They also offer programs to help the spouse/family feel companioned with as they grieve, and supported as they go about rebuilding their lives. These include:

- Seminars
- Youth Programs
- Retreats
- Peer Mentors
- Online Community
- Care Groups, among others

~~###~~

**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](http://www.nhpco.org/pediatrics)

## 10 Tips on Talking to a Child after a Tragedy

**Diane Snyder Cowan, MA, MT-BC, CHPCA**

Director, Western Reserve Grief Services

Hospice of the Western Reserve, Inc.

Cleveland, OH

[hospicewr.org/griefandloss](http://hospicewr.org/griefandloss)

Tragic events such as the recent mass shooting at a Florida high school are difficult for anyone to comprehend and process. Locally and across the country, we collectively mourn the loss of life every time such a senseless tragedy occurs. In addition, children's own sorrow, fear and despair can be heightened as they watch and hear about the plight of grieving students, teachers and the affected community in school, on social media and the nightly news. As parents, it is important that we reassure our children that though we hear about these tragedies, we, their school and other adults in their world are always working to ensure their safety.

Diane Snyder Cowan, Director of Western Reserve Grief Services, offers these tips for talking to children after a tragedy:

1. Process through the tragedy yourself before talking with your children.
2. Remain calm. Your ability to manage your fears and emotions will help your child manage their feelings and build healthy coping skills.
3. Allow yourself and your child/children to be angry and question why horrible things like this happen in the world.
4. Be patient and available to answer questions honestly and in an age appropriate manner. It is okay if you cannot answer certain questions due to a lack of information or comfort level. "I don't know," is an acceptable answer!
5. Be honest about your feelings. Sharing your feelings and fears with your children gives them a sense of hope and validates their emotions.
6. Consider how this event might trigger grief reactions related to recent deaths or other traumatic events in your life.
7. Remember that your child may need to revisit the event and ask the same question repeatedly in an effort to understand their emotions and process the event.
8. Provide your child/children with a safe place to share their feelings, discuss nightmares they are having as a result of the tragedy and fears.
9. Take a break from the media exposure. Turn off the TV, radio, refrain from using Facebook and Twitter and limit adult conversation.
10. Ask about the emergency security protocol at your child's school. Share these plans with your child/children to promote a sense of safety in their school.

Following such a crisis, expert on-site support frequently plays an instrumental role in helping students and faculty navigate the painful experiences of trauma, grief and loss. Locally, the bereavement center at Hospice of the Western Reserve – now called Western Reserve Grief Services - has offered a Crisis



### 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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

Response Program to provide immediate, on-site crisis response to deaths in the school communities of Northern Ohio for more than 15 years.

The program has been utilized by the Cleveland Metropolitan School District and many others. The services are available to any school system in the nonprofit agency's service area. Trained bereavement professionals are available to provide on-site response. A single phone call from the school is all it takes to mobilize resources. In a typical year, trained grief and trauma support specialists from the organization deliver immediate on-site crisis support to 1,000 students and 250 adults.

In coordination with the school, trained and experienced bereavement professionals are available to lead classroom, small or large group student discussions, hold informational meetings with parents, provide individualized sessions during a crisis response and offer guidance to teachers and staff. Follow-up services such as memorial activities, small support group interventions and educational programs are available as needed. Proactive services are also offered including crisis response planning.

The program is one of the many ways Hospice of the Western Reserve extends its expertise in end-of-life care and bereavement support to the community at large.

For more information on these services and to obtain additional resources on speaking with children on grief, visit: [hospicewr.org/griefandloss](http://hospicewr.org/griefandloss).

~~###~~



**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](http://www.nhpco.org/pediatrics)

# TALKING WITH CHILDREN AND TEENS ABOUT SUICIDE AND VIOLENT DEATHS

Be In A Neutral, Safe Setting

Have Some Of Their Favorite Adults Present

Use Age Appropriate Language

Deliver Information in Bite-Size Pieces

Be Prepared for Mixed Emotions

Give Physical And Creative Outlets

It's Ok To Talk About The Person Who Died

## 3-6 YEAR OLDS



**Suicide:** They made their body stop working.

**Homicide:** Someone hurt his body so bad that his body stopped working and he died.

**How To Help:** Play, physical activity, creative outlets, maintain routines and structure, reassure them that they are safe and loved

**Normal Grief Responses:** Regressive behaviors, repetitive questions/play, crying, clinginess, increase in fears, acting out behaviors, unclear about finality of death

## 7-11 YEAR OLDS



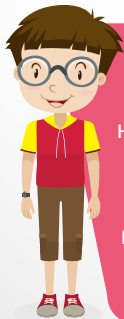
**Suicide:** Your person caused their own death. This is called suicide.

**Homicide:** Someone killed your dad. He is no longer living.

**How To Help:** Play, physical activity, creative outlets, maintain routines and structure, answer questions truthfully, address issues around fears and safety, validate their experience without judgement

**Normal Grief Responses:** Crying, shocked, confused, scared, angry, sad, acting out, regression, isolation, declining grades, curious, can feel stigma, is clear about finality of death

## 12-17 YEAR OLDS



**Suicide:** They died by suicide or, he killed himself.

**Homicide:** She was murdered.

**How To Help:** Give them space, connect them with peers who have experienced a death, maintain routines, disclose details when asked, be a good role model, ask them what they need

**Normal Grief Responses:** Angry, confused, scared, acting out, promiscuous behaviors, isolation, tearful, declining grades, can feel stigma, depressive like symptoms, changes in sleeping, eating and moods



If possible, have child's favorite adults present.

**Favorite adults**

Disseminate information with minimal details. Answer questions as they arise; be clear and concise. If you do not know the answer, it is ok to say, "I don't know, but I will tell you when I do know."

**Bite-size pieces**

Make sure to give time for physical activity and creative outlets. Play is a child's language and will allow them to process the heavy news.

**Provide outlets**



**Neutral, safe setting**

Deliver information in a quiet, familiar setting such as a living room or kitchen.

**Age appropriate language**

Avoid euphemisms such as "passed away," "went to sleep," or "went away". These terms are confusing to a young child. Instead, use words like "died," "dead" or "killed." Keep verbiage simple and easy to understand.

**Mixed emotions**

Be prepared for a variety of responses such as, shocked, confused, indifferent, angry, sad, anxious, stoic, withdrawn, and isolative. Children may wish to return to regular activities right away (i.e., school, sports, social engagement, peer interaction) while others will want a respite; allow them to decide.

**Talk about them**

It's ok to talk about the person who died. Share memories but be respectful of child's desire to share/receive memories or stories. Make sure you aren't using your child as your sounding board for your grief work. Share truthfully, as a child is ready to hear more.

## EXPLAINING SUICIDE TO CHILDREN

"It is difficult to understand why someone would want to end his or her life on purpose. But what we know is that just like people can get sick in their bodies, such as pain in their stomach, people can also get sick in their brain. This can cause them to feel very sad and lonely for a long time.

When people feel like this, they sometimes think about hurting themselves or even killing themselves. That is what your mom did. This is called suicide. Do you have any questions?"



## EXPLAINING HOMICIDE TO CHILDREN

"There are people in this world who might make a decision to hurt someone else on purpose. Someone killed your dad and he is no longer alive. It can be difficult to understand why someone would want to cause others harm like this. This is called homicide. Do you have any questions?"



Source created by:

Lynn M. Snyder, LPC, ATR-BC, FT  
Common Ground Grief Center  
67 Taylor Avenue~ Manasquan, NJ 08736  
732-606-7477  
[www.commongroundgriefcenter.org](http://www.commongroundgriefcenter.org)

Melissa Lunardini, MA  
The Elizabeth Hospice  
500 La Terraza Blvd. Ste. 130  
Escondido, CA 92025  
760-737-2050  
[www.ehospice.org](http://www.ehospice.org)



# Talking to children about terrorist attacks and school and community shootings in the news

This guide offers advice on how to talk to children about tragic events, such as shootings and terrorist attacks, that they are likely to hear about at school and/or on the news.



## THEY WILL ASK WHAT HAPPENED

Children and teenagers are better able to cope with upsetting news when they understand more about the event. They need information just as adults do. Begin by asking what they already understand about what happened. They have likely heard about it on TV, on the internet or social media, at school, or from their friends.

However, much of their information may not be accurate. As they explain what they know about the event, you can figure out what it is they don't already know or understand. Look for misunderstandings or frightening rumors. Tell the truth and do not try to mislead them "for their own good." Children and youth of different ages understand and react differently according to their developmental age and unique personal experiences. It is important to remember that we cannot assume that children's worries are the same as our own. When we listen to children and come to understand their feelings and worries, we can better help them make sense of these experiences and how they affect us all.

The amount of details that children will find useful will depend upon their age. The older the child is, the more details will likely be needed to answer their questions and address their concerns. Provide the basic information in simple and direct terms and then ask for questions. Take your cues from children in determining how much information to provide. Older children may wish to discuss the larger implications of the event. Provide reassurance whenever possible. Our government, police, and schools are taking steps to protect us from something like this happening again and to keep us safe. Children often look for reassurance that they are now safe after such graphic reminders of danger and hatred.

Terrorist acts and school and community shootings remind us all that we are never completely safe – but now is the best time

to reassure children that they can and should feel safe in their school, in their home, and in their community. While it is useful for children to know enough about what has happened to feel that they understand what has occurred and what they should do, it isn't helpful for children (or adults) to be exposed to graphic images or information or to continuous or repetitive media coverage. Such images and details are often included in coverage of the event on television, radio and print media, as well as in social media and elsewhere on the internet. Limit the amount of exposure to media coverage and discussion in social media. In the immediate aftermath of a crisis event, it's a good time to turn off television, computers, and smart phones and come together as a family and community for discussion and support.

## COULD I HAVE DONE ANYTHING TO PREVENT THIS?

After a tragic event, we all wonder what we and others could have done to prevent this from happening.

Even when it is obvious that there is nothing children could have done to prevent or minimize the crisis, they may still feel helpless and wish they could have changed what happened. Let children know that this is a common reaction; we all wish that there is something we could have done to prevent this or any tragedy. Instead, suggest that together you can concentrate on what can be done now to help those most directly affected and to promote safety, tolerance and acceptance in our communities.

## WHOSE FAULT IS IT?

In some ways, blaming is a way to feel as if you can regain control of uncomfortable feelings and a sense of personal risk.

While it is natural to engage in thoughts of blame, this doesn't ease the immediate feelings of grief and fear nor does it provide any solutions for the future. It is understandable that people would be angry at the individuals who commit acts of terrorism and hatred, but sadly sometimes people are also angry at those people that are easier to find and blame – such as people who look like they might belong to a larger group that includes those who were responsible.

Children should be told that although it is common to feel angry, terrorists and those that commit violent acts do not represent a particular racial, ethnic, religious or other group. The violence may also cause children and teenagers to become frightened that they may be targeted by people because they may fear others do not approve of who they are. We as Americans take pride in having members of many different races, religions, sexual orientations and ethnic backgrounds. This is a time to join together and continue to be inclusive, accepting and supportive of all who seek peace.

---

## IS THIS GOING TO CHANGE MY LIFE?

This is a question that we all struggle to answer, not only for children but also for ourselves. Especially in difficult times, children may act immaturely. Teenagers may want to spend more time with their peers. Children and teenagers are often very concerned about themselves. When there is a tragic event, they may become even more concerned about what affects them personally. Adults who do not understand this may see this as being selfish or uncaring. It is important to make children feel comfortable in asking questions and expressing their feelings.

Expect children to think more about themselves for the time being. Once they feel reassured that they are being listened to and their needs will be met, they are more likely to be able to start to think about the needs of others.

---

## CAN I HELP?

Once children start to feel safe and understand what is going on, many will want to help. While there may be little that they can do now to help the immediate victims of a particular crisis, there is a lot they can do to help. They can start by taking care of themselves – telling you when they are upset or worried, being honest and open. They can also offer help to other members of their community – their friends and classmates, their teacher, and other adults. Over time, they can think about how they, along with other members of their community, might be able to do something helpful for the victims and survivors.

---

## I DON'T WANT TO MAKE THINGS WORSE, SO SHOULD I SAY NOTHING INSTEAD?

Often what children and teenagers need most is to have someone they trust listen to their questions, accept their feelings, and be there for them. Don't worry about knowing the perfect thing to say – there is no answer that will make everything okay. Listen to their concerns and thoughts, answer their questions with simple, direct and honest responses, and provide appropriate reassurance and support. While we would all want to keep children from ever having to hear about something like this, reality does not allow this. Being silent on the issue won't protect them from what happened, but only prevent them from understanding and coping with it. Remember that answers and reassurance should be at the level of the child's understanding.

---

## WHAT IF THIS UPSETS THEM?

During these discussions, children may show that they are upset – they may cry, get anxious or cranky, or show you in some other way that they are upset. Remember, it is the events that are upsetting them, not the discussion. Talking about the event will permit them the opportunity to show you how upset they really are. This is the first step in coping with their feelings and adjusting to their new understanding of the world. Pause the conversation periodically so that you can provide support and comfort and ask if they wish to continue the discussion at another time. But it is helpful for children to realize that it is okay to show you when they are upset. Otherwise, they may try to hide their feelings and will then be left to deal with them alone.

---

## SHOULD I BRING IT UP EVEN IF THEY DON'T ASK QUESTIONS? WHAT IF THEY DON'T SEEM TO WANT TO TALK ABOUT IT?

When a major crisis of this nature occurs, it is a good idea to bring the topic up with children, no matter how young they are. At first, older children and teenagers may tell you that they don't want to or need to discuss it. It is generally not a good idea to force them to talk with you, but do keep the door open for them to come back and discuss it later. Be available when they are ready to talk, but let them choose the time.

Often children find it easier to talk about what other children are saying or feeling instead of talking about themselves.

---

## HOW CAN I TELL IF CHILDREN NEED MORE THAN I CAN PROVIDE? WHERE SHOULD I GO FOR SUCH HELP?

When a terrorist attack or school or community shooting occurs, most people will be upset. However, should children continue to be very upset for several days and be unable to recover from their fears, or if they are having trouble in school, home or with their friends, then it is a good idea to speak with someone outside the family for advice. The event may have triggered other distressing experiences, worries or concerns they have. You may wish to speak with a teacher or school counseling services, pediatrician, mental health counselor or member of the clergy for advice. Please remember that you shouldn't wait until you think they need counseling – you should take advantage of counseling and support whenever you think it will be helpful.

---

## IF I HAVE MORE QUESTIONS, WHERE CAN I TURN FOR ANSWERS?

For more resources, visit [SchoolCrisisCenter.org](http://SchoolCrisisCenter.org), the website of the **National Center for School Crisis and Bereavement (NCSCB)**, or contact the Center at 1-877-536-2722.

For information on how to support children who are grieving, visit [GrievingStudents.org](http://GrievingStudents.org), the website of the **Coalition to Support Grieving Students**.



# Interdisciplinary Guidelines for Care of Women Presenting to the Emergency Department with Pregnancy Loss

---



## Abstract:

Members of the National Perinatal Association and other organizations have collaborated to identify principles to guide the care of women, their families, and the staff, in the event of the loss of a pregnancy at any gestational age in the Emergency Department (ED). Recommendations for ED health care providers are included. Administrative support for policies in the ED is essential to ensure the delivery of family-centered, culturally sensitive practices when a pregnancy ends.

## Definitions:

- **Pregnancy Loss:** Depending on what the ending of a pregnancy means to a woman, any of the following terms may be appropriate: products of conception, fetal remains, miscarriage, stillbirth, and baby.
- **Emotional Emergency:** The term “emotional emergency” is used to describe an event that is traumatic emotionally and provokes an emergent need for support.

## Abbreviations:

- ED - emergency department
- ER - emergency room
- D and C- dilatation and curettage
- UNOS - United Network for Organ Sharing

## Introduction:

When a woman comes to the ED with the threatened or impending loss of a pregnancy at any gestational age, she is experiencing an event with emotional, cultural, spiritual, and physical components.<sup>1-9</sup> A challenge exists in simultaneously providing treatment that is both physically and emotionally therapeutic, including holistic and spiritual support for the woman and her family, and providing bereavement care.

## The following principles and practices are recommended:

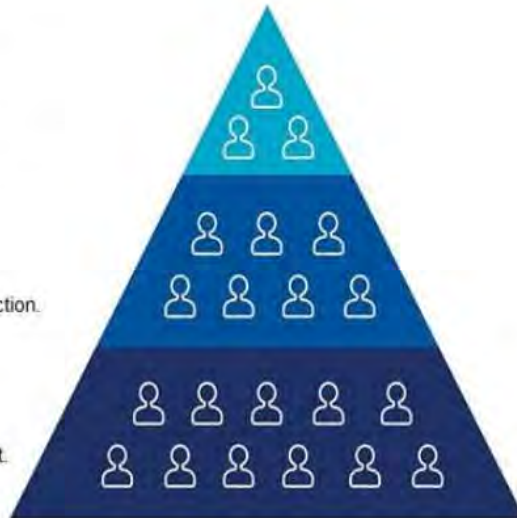
1. The ED health care team uses a relationship-based, patient-centered, family-focused, and team-oriented approach. The team provides personal, compassionate, and individualized support to women and their families while respecting their unique needs, including their social, spiritual, and cultural diversity.<sup>10-11</sup>

2. The ED health care team provides effective, timely, attentive, and sensitive care to all dying patients and their families, including families experiencing a perinatal death. This care is defined as anticipation and management of all symptoms related to the death or impending death of an unborn or prematurely born baby and the provision of physical, emotional, and spiritual comfort to the woman and her family. <sup>12</sup>
3. The ED team provides a coordinated response, including sensitive triage as an “emotional emergency” <sup>13-14</sup> and a potentially serious physical event.
4. The ED health care team should provide privacy and safety for the woman and family. <sup>15-16</sup> A suggested location is the room where private or forensic pelvic exams are done.
5. Each facility should use a recognizable marker that designates pregnancy loss. <sup>17</sup> The marker may be used on the room, stretcher, bed, medical record, or any other item deemed appropriate. All health care personnel (e.g., medicine, nursing, social work, chaplaincy, pathology, laboratory, ultrasonography, radiology, and patient transport) should be taught to recognize this marker and provide sensitive care in response.
6. Transportation to and from ultrasound to confirm perinatal death should be done with dignity and compassion, and the presence of a loved one, support person, or advocate should be encouraged.
7. Bad news should be delivered with compassion and concern, and how to do so effectively should be included in the training of all health care providers. Cultural sensitivity and individual circumstances are important; some families may not consider this to be a loss and others may be deeply affected. <sup>17</sup> To determine the pregnancy loss meaning, providers can simply ask, “How are you feeling about this?” <sup>18</sup> If the provider is uncomfortable, enlisting the assistance of a colleague is recommended.
8. Many families consider perinatal loss to be as significant as the loss of a living child. <sup>3, 6, 19</sup> Providers should attempt to determine how the woman and family consider this loss, i.e., do they view the end of this pregnancy as a minor event or do they view this as the significant loss of a baby?
9. The ED health care team should identify and notify the obstetric provider (if one exists) of the death or potential death. This is important for follow up obstetric care and to avoid having the woman continue to receive communications from the provider regarding prenatal screening tests and pregnancy classes when she is no longer pregnant. Also, the provider may wish to order specific testing on the mother or fetus. An Rh immunoglobulin injection is ordered as is policy of that institution. <sup>20</sup>

10. Sorrow for the pregnancy loss should be expressed by anyone in close contact with the family, unless all family members have stated that this is not a sorrowful event to them.
11. When providing physical care of the woman, the provider should tell her what to expect in terms of the normal clinical course of post-pregnancy loss recovery,<sup>21</sup> including vaginal discharge, possible lactation and breast care,<sup>22</sup> hormonal changes and their effects, and postpartum depression and anxiety. Sanitary napkins and ice packs may be provided for home care. After-care instructions should include being told that they should see a health care provider as soon as possible if the following occurs:<sup>23</sup> significant bleeding, such as clots the size of a plum, accompanied by lightheadedness or fainting; fever; or foul-smelling discharge or uterine tenderness.
12. If a woman needs a dilatation and curettage (D and C) procedure,<sup>24</sup> it is recommended that this be done in a sterile and calm environment outside of the emergency department. If the procedure must be done in the ED, the woman should have access to the same level of comfort, sedation, and nursing support as is the standard of care outside of the ED.
13. Some families may wish to bury the remains of a baby after a D and C. Products of conception should not be discarded automatically with medical waste without prior discussion.<sup>25</sup>
14. Patients and families should be given specific information for dignified disposition of any product of conception. This discussion is now mandated by law in several states and countries.<sup>26</sup> Patients and families should have choices about taking fetal remains home; having them buried or cremated; or leaving them at the hospital for respectful disposition according to local, state, and federal laws. In some states, remains can be released only to a funeral home that would then involve the family in decision making. When hospital staff members are transporting miscarried babies or remains to the laboratory or the morgue, this should be done with respect, in the same quiet and dignified manner that an adult body would be transported.
15. If the pregnancy does not end in the ED and patient is sent home to “watch and wait,” the ED team should fully inform her about what may happen physiologically if the pregnancy does come to an end, and at what point she might want to return to the hospital or her health care provider.<sup>27</sup> The team should explain how to use a hat or strainer when using the toilet, in case tissue, baby, or placenta is passed. Such collection items should be offered to the mother in a convenient and dignified manner. Simple written instructions in the preferred language are essential.
16. Emotional support can be given as adapted from the Kazak’s Pediatric Preventative Psychosocial Health Model.<sup>28</sup> All women may be given grief and bereavement materials from organizations listed below.

Adapted from Stepped Care Pyramid, Kazak, 2006

- **Clinical/Treatment Level**  
Woman is experiencing persistent or escalating distress.  
High risk factors.  
Referral is made to trained mental health professional.
- **Targeted Patients**  
Woman is in acute distress.  
Hospital Chaplain or Social Worker is called to assist.  
Perinatal Bereavement Counselor makes follow-up connection.
- **Most Patients - Universal Emotional Support**  
Women and families may be distressed but are resilient.  
Nurses and Physicians in the ED offer comfort and support.



17. Specific education<sup>17</sup> regarding the management of loss of a desired pregnancy should be provided to all ED personnel, including physicians, nurses, and technicians; and all trainees, such as emergency medicine, obstetric, and pediatric residents, medical students, nursing students, and emergency nurse orientees. Education should include:

- Giving the news in a culturally competent, compassionate, supportive, and honest manner
- Assessing the meaning of the pregnancy loss to the woman and family, and directing care accordingly
- Informing the family that grief takes different forms and timeframes for each culture and each individual within a culture, and giving them permission to grieve in their own way<sup>18</sup>
- Teaching how nurses and providers can learn to feel comfortable with showing products of a miscarriage or fetal loss to a woman or her family should she ask for this (See further description in Table 1).
- Providing support with decision-making about procedures, family involvement, memory-making, and saying goodbye
- Providing names and contact information for local grief counselors or pregnancy loss support groups and community caregivers dedicated to pregnancy loss support

18. Grieving parents and their families can be offered bereavement care. This can include cultural or spiritually appropriate support, such as a baptism or blessing. Parents may wish to take pictures and a digital camera in the ED may be helpful. Other options are available for babies of larger sizes. Skin-to-skin holding, bathing and wrapping the baby in blankets or dressing the baby in

specially made clothing may be appropriate. Families can be provided a memory box which may have a lock of hair, hand and foot prints, or other keepsakes.<sup>29-31</sup>

19. In most cases of pregnancy loss at greater than 20 weeks gestation, women are transferred to the maternal child department, where bereavement support is available. In cases in which the patient will remain in the ED for the duration of care, ED personnel should know the processes for:
  - Completion of state-mandated birth, death, and/or stillbirth certificates
  - Contacting the state UNOS organization, if gestation allows for consideration of tissue or organ donation
  - Policy related to sending the placenta/cord to Pathology
  - Maternal toxicology screen, if indicated by locale
  - Lab work for genetic or other studies
  - If gestational age permits, a gentle discussion of full or partial autopsy of the body or placenta and obtainment of necessary consent
  - Discussion related to disposition of remains in a culturally competent and sensitive manner that offers all options legal in the state, and provision of written materials related to dispositions that are written at patient's literacy level
  - Information regarding hospital memorial services and/or burial ceremonies, if available
  
20. Ongoing perinatal bereavement care in-services should be available, and materials such as supplies and policies and procedures should be reviewed. Many of the following organizations provide pregnancy loss training for ED personnel. All provide selections of written material that may be ordered for patients.
  - Gundersen Health System Resolve Through Sharing (<http://www.gundersenhealth.org/resolve-through-sharing> )
  - SHARE Organization ([www.nationalshare.org](http://www.nationalshare.org))
  - A Place to Remember ([www.aplacetoremember.org](http://www.aplacetoremember.org))
  - Babies Remembered ([www.BabiesRemembered.org](http://www.BabiesRemembered.org))
  - Centering Corporation ([www.centering.org](http://www.centering.org))
  - The Miscarriage App (a mobile phone application for iPhone and Android phones)
  - Position Statements and Practice Guidelines for health care practitioners from the Pregnancy Loss and Infant Death Alliance ([www.PLIDA.org](http://www.PLIDA.org))
  
21. Hospitals should provide the ED with human resources to assist the ED team, such as a perinatal bereavement team member, chaplain, social worker, behavioral health staff, maternal child nurse, and hospice or palliative care staff. The assigned bereavement coordinator within or outside of the ED may follow up with a phone call to the family at one week and text, email, or phone the family at one month.<sup>17</sup>

22. Emotional support for ED staff who care for these patients and families is important. Staff should ask for help in an immediate situation if needed. Debriefing after a difficult loss situation is encouraged.<sup>32</sup> Self-care is essential for ED personnel who often have difficult or troubling cases. The hospital chaplain or social worker should be called on as needed. An appointment with the facility's Employee Health may be helpful.

---

*Funding from a Northern California Kaiser Permanente Nursing Research Community Benefits Grant and support from the National Perinatal Association is acknowledged.*

History of how this position statement was created can be found in Catlin, A. (2017). Creation of Interdisciplinary Guidelines for Care of Women Presenting to the Emergency Department with Pregnancy Loss. *Journal of Perinatology*, in press.

Participants in the National Perinatal Association Summit that created these guidelines can be found in Catlin, A. (2017). Interdisciplinary Guidelines for Care of Women Presenting to the Emergency Department with Pregnancy Loss. *MCN, The American Journal of Maternal Child Nursing*, in press.

## References:

1. Evans, R., Emotional care for women who experience miscarriage. *Nursing Standard*, 2012. 26(42): p. 35-41.
2. Hughes, K. and U.A. Goodall, Perinatal bereavement care: Are we meeting families' needs?. *British Journal of Midwifery*, 2013. 21(4): p. 248-253.
3. Kavanaugh, K., D. Trier, and M. Korzec, Social Support Following Perinatal Loss. *Journal of Family Nursing*, 2004. 10(1): p. 70-92.
4. Kuebelbeck, A. and D.L. Davis, *A Gift of Time, Continuing Your Pregnancy When Your Baby's Life is Expected to Be Brief*. 2011, Baltimore: Johns Hopkins.
5. Ilse, S. and L. Burns, *Miscarriage: A Shattered Dream*. 2015, Minneapolis: Wintergreen Press.
6. Koziol-Mclain, J., et al., An investigation of emergency department patients' perceptions of their miscarriage experience. *Journal of Emergency Nursing* 1992. 18(6): p. 501-504.
7. Lee, C., 'She was a person, she was here': The experience of late pregnancy loss in Australia. *Journal of Reproductive & Infant Psychology*, 2012. 30(1): p. 62-76.
8. Murphy, F. and J. Merrill, Negotiating the transition: Caring for women in the experience of early miscarriage. *Journal of Clinical Nursing*, 2009. 18(11): p. 1583-1591.
9. Swanson, K., et al., Contexts and evolution of women's responses to miscarriage during the first year after loss. *Research In Nursing & Health*, 2007. 30(1): p. 2-16.
10. Arshad, M., A. Horsfall, and R. Yasin, Pregnancy loss-Islamic perspective. *British Journal of Midwifery*, 2004. 12(8): p. 481-484.
11. National Perinatal Association, Shah, M. Editor. *Transcultural Aspects of Perinatal Care: A Resource Guide*, 2nd Ed . 2003.
12. Wool, C., Clinician confidence and comfort in providing perinatal palliative care. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 2013b. 42(1): p. 48-58.
13. Lee, C. & Slade, P. Miscarriage as a traumatic event: A review of the literature and new implications for intervention. *Journal of Psychosomatic Research*, 1996, 40 (3), 235-245.
14. Klein, S; Cumming, GP; Lee, AJ; Alexander, DA; Bolsover, D. Evaluating the effectiveness of a webbased intervention to promote mental wellbeing in women and partners following miscarriage, using a modified patient preference trial design: an external pilot. *BJOG: An International Journal of Obstetrics & Gynaecology*, 2012, 119 (6),762-767.
15. Zavotsky, K., et al., Early pregnancy loss and bereavement in the emergency department: staff and patient satisfaction with an early fetal bereavement program. *Journal of Emergency Nursing*, 2013. 39(2): p. 158-161.
16. Dougherty, N., Better ways to treat women with miscarriages: Using a patient complaint to improve emergency department care. *Journal of Emergency Nursing*, 1994. 20(6): p. 521-527.
17. Wilke, J. and R. Limbo, *Bereavement Training In Perinatal Death. Resolve through Sharing Manual*. 2012, La Crosse, Wisconsin: Bereavement Services Gundersen Health System.

18. Rudd, R. and L. D'Andrea, Professional support requirements and grief interventions for parents bereaved by an unexplained death at different time periods in the grief process. *Int J Emerg Ment Health.*, 2013. 15(1): p. 51-68.
19. Layne, L., *Motherhood Lost: A Feminist Account of Pregnancy Loss in America.* 2003, Abingdon, Oxon UK: Taylor & Francis.
20. Karanth, L., Jaafar, S., Kanagasabai, S. Anti-D administration after spontaneous miscarriage for preventing Rhesus alloimmunisation. *Cochrane Database of Systematic Reviews* 2013,
21. White, H. And D. Bouvier, Caring for a patient having a miscarriage. *Nursing* 2005, 2005. 35(7): p. 18-19.
22. Busta-Moore, D., & Catlin, A. Lactation Suppression: Forgotten aspect in care of the mother of a dying child. *Pediatric Nursing*, 2003. 29(5).
23. Staff, Healthwise. Miscarriage: Care Instructions. Kaiser Permanente Health Encyclopedia 2015; Available from: [https://healthy.kaiserpermanente.org/health/care/consumer/health-wellness/conditionsdiseases/he2/!ut/p/a1/hdBNb4JAEAbg39IDxzIDaxF7A1sBKX6SSvfSLLACybpL6Fbiv1eqPfTQQLdJnmTd4BCBISyY1Mx3SjxLBT53M23y593\\_lwCMIZRuFLYMVVYKPrwA7mQCu\\_h8h\\_8UWvdPhoYKGGk5IJ3XJa8452BQAt9ajlkbXMP1n1TQva9H9vEumfZNBtMtOj6kcvlVAjV8rJhsP\\_OBZid8n4I8WRO3Apox\\_fDrVmrLw1Z3\\_dmpVQluFmow6UN\\_Vt4OZq4GCXTcBotYsTAvoGVh5Gb4JOFHnEwclISj5OFhcHoBpBE6-vLVg5ebJzG75OYIP4m4D\\_jlbQH90TE8Y1vcmfzun44A-6IJbM!/dI5/d5/L2dBIS9nQSEh/](https://healthy.kaiserpermanente.org/health/care/consumer/health-wellness/conditionsdiseases/he2/!ut/p/a1/hdBNb4JAEAbg39IDxzIDaxF7A1sBKX6SSvfSLLACybpL6Fbiv1eqPfTQQLdJnmTd4BCBISyY1Mx3SjxLBT53M23y593_lwCMIZRuFLYMVVYKPrwA7mQCu_h8h_8UWvdPhoYKGGk5IJ3XJa8452BQAt9ajlkbXMP1n1TQva9H9vEumfZNBtMtOj6kcvlVAjV8rJhsP_OBZid8n4I8WRO3Apox_fDrVmrLw1Z3_dmpVQluFmow6UN_Vt4OZq4GCXTcBotYsTAvoGVh5Gb4JOFHnEwclISj5OFhcHoBpBE6-vLVg5ebJzG75OYIP4m4D_jlbQH90TE8Y1vcmfzun44A-6IJbM!/dI5/d5/L2dBIS9nQSEh/).
24. Staff, Healthwise. Dilation and Curettage: Before Your Procedure. Health Encyclopedia Kaiser Permanente 2015; Available from: [https://healthy.kaiserpermanente.org/health/care/consumer/healthwellness/conditionsdisease/s/he2/!ut/p/a1/hc8xT8MwEAXg38KQEfM5bk3ClhbquFbaUioIXpBJrCaSczIFOXfU6AMDjbnvTp7h3RpCLam2N3MLHrvXGfWfPn5ep-M5\\_THEIUS8jiRIBfxQQpJ49kRfTB9S9f-KmNMVwnSFD3PlOfBsbO9ghAdHte9eQ6q2hWTb7z5o4Bkuq1hoX20vr67F2fbBNZ04X9e9Sm2m\\_WQpalyHXChCTM9jmkGmJGUXOOCTfM3VVrinE9AzA5N33W1uOk1V79ZApBvxswB-Tg4TXdGTuGG53-cUHqniUxw!/dI5/d5/L2dBIS9nQSEh/](https://healthy.kaiserpermanente.org/health/care/consumer/healthwellness/conditionsdisease/s/he2/!ut/p/a1/hc8xT8MwEAXg38KQEfM5bk3ClhbquFbaUioIXpBJrCaSczIFOXfU6AMDjbnvTp7h3RpCLam2N3MLHrvXGfWfPn5ep-M5_THEIUS8jiRIBfxQQpJ49kRfTB9S9f-KmNMVwnSFD3PlOfBsbO9ghAdHte9eQ6q2hWTb7z5o4Bkuq1hoX20vr67F2fbBNZ04X9e9Sm2m_WQpalyHXChCTM9jmkGmJGUXOOCTfM3VVrinE9AzA5N33W1uOk1V79ZApBvxswB-Tg4TXdGTuGG53-cUHqniUxw!/dI5/d5/L2dBIS9nQSEh/).
25. Limbo, R., K. Kobler, and E. Levang, The respectful disposition in early pregnancy loss. *MCN*, 2010. 35(5), 116-122.
26. Human Tissue Authority, 2015. United Kingdom. Guidance on the disposal of pregnancy remains following pregnancy loss or termination. [https://www.hta.gov.uk/sites/default/files/Guidance\\_on\\_the\\_disposal\\_of\\_pregnancy\\_remains.pdf](https://www.hta.gov.uk/sites/default/files/Guidance_on_the_disposal_of_pregnancy_remains.pdf)
27. Limbo, R., Glasser, J. & Sundaram, M. Dimensions of a Woman's Experience of Inevitable Miscarriage. *JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing*, 2014. 43(Supp 1): p. S72-73
28. Kazak, A. E., Kassam-Adams, N., Schneider, S., Zelikovsky, N., Alderfer, MA., & Rourke, M. (2006). An Integrative Model of Pediatric Medical Traumatic Stress. *J. Pediatr. Psychol.* 2006. 31(4): 343-355.



29. Carlson, R., Helping Families Create Keepsakes When a Baby Dies. *International Journal of Childbirth Education*, 2012. 27(2): p. 86-91.
30. Kobler, K., R. Limbo, and K. Kavanaugh, Meaningful moments: the use of ritual in perinatal and pediatric death. *MCN: The American Journal of Maternal Child Nursing*, 2007. 32(5): p. 288-297.
31. Maloney, C. Critical Incident Stress Debriefing and Pediatric Nurses: An Approach to Support the Work Environment and Mitigate Negative Consequences, *Pediatric Nursing*, 2102, 38(2), 110-113.

Table 1. Recommendations for ED Nurse on Seeing and Showing After Miscarriage

### Seeing and Showing

Some women choose to see and/or hold the remains after a miscarriage; others do not. As she is making that decision, hearing someone say, “I don’t think you should” or “We don’t allow that here,” or, trying to induce her to hold the baby when she prefers not to, can be harmful. Such statements may increase the woman’s sense of powerlessness and create a lifetime of wondering. Patients often wonder how the remains/baby will be cared for following miscarriage. You could say, “The baby will go to the laboratory (in some facilities this is the morgue). The transport will be made with dignity and we have this specially designed fabric bag for the transport.” You can say, “You can see your baby whenever you want.” The facility may be working towards an annual burial service or have one for inclusion of the remains.

### Contents of the Uterus after a Loss

In order to anticipate what the remains will look like, the nurse or health care provider reflects with the pregnant woman on what she can expect to see: How many weeks’ gestation was the pregnancy (the longer the pregnancy, the greater the likelihood of a visible baby)? In early pregnancy, there may be only blood clots, perhaps the size of a plum, whitish tissue and watery fluid. How long has the baby been dead, or how long has the pregnancy been over, or how long did it take to have the miscarriage (A pregnancy over for a period of time may result in a macerated product and decomposing of conception when passed)? If the diagnosis of this miscarriage was a “blighted ovum,” this means there was no fetal pole and the embryo/fetus did not develop. The uterus appears empty on ultrasonography. Therefore, there would be no embryo or fetus, but there could be placental tissue. If gestation continued for a significant period, there will be a formed fetus or baby that is passed.

Careful explanation from the provider can set the tone. A sensitive statement from the nurse or care provider would be, “I want to help you be prepared for what you will see. Based on what has happened so far, what are you expecting the remains/your baby to look like?” Then verify or clarify. “Because your miscarriage happened so early, you usually will see tissue, blood, liquid, and maybe a formed (but very tiny) baby. I will let you know what you will see so you feel prepared, and I will be with you if you’d like me to be.” Or “Because this miscarriage happened late, there will be a very small baby to see.”

### Viewing Uterine Contents after Surgical Intervention

Surgery (dilation and curettage; dilation and evacuation) typically results in the tissue being disrupted so that an identifiable baby comes out in parts. It might be difficult to see this for both the staff member and the woman. Some nurses have made footprints for the mother

when possible as a cherished memento. Respectful handling of tissue after miscarriage or surgery includes placing the remains on something soft (blanket, gauze) or within a special box with a blanket. You might say “We have a special purple box with a tiny blanket inside for your baby’s remains. “

### Guidelines for Working with Laboratory and Morgue Staff

If one or both parents wish to see the baby after an identifiable embryo/fetus/baby has been placed in formalin in the laboratory or morgue, the most important aspect of this viewing is that the baby’s body first be placed in 100% alcohol for a period of time.

Formalin darkens skin tones; alcohol returns the skin to its normal color (the larger the body, the longer this takes). This requires written guidelines regarding rinsing the baby’s body if it has been in formalin; guidelines for parents who wish to remove the baby from the laboratory; checking on state and hospital guidelines, and establishing strong, enduring relationships with laboratory/morgue staff. Those who work in the laboratory or morgue should understand the tremendous difference they can make in the lives of parents.

### The Importance of Respectful Disposition

Clinical experience and research consistently demonstrate that anything that could be interpreted as disrespectful to the parents’ baby should always be avoided when showing the remains, such as use of emesis basins, buckets, bedpans and suction canisters. If you do not have a special box or blanket, use something soft, such as gauze or a soft cloth. Even if your ED has only curtains separating one patient from another, provide privacy through a soft tone of voice, being seated, engaging both parents or the mother and her support person, assess the meaning of the miscarriage (e.g., if the woman/mother uses the term “baby” or “my baby,” then the provider should use those terms as well--but not before the patient/mother does).

Explain when questions are asked, but avoid talking nonstop while the parents are being with their baby. Ask, “Would you like me to step out for a few minutes so you have some time alone?”

### This single snapshot memory stays with parents for a lifetime.

Compassionate and respectful care in this singular moment when they see their baby who was miscarried are critical. Hold in mind that you are a part of a time in your patient’s life in which she knows very little of what to expect. She will remember always the difference you made.

**Author Table 1:** Rana Limbo, PhD, RN, CPLC, FAAN, Resolve Through Sharing®, with assistance from Cathy Mikkelson Fisher, MA, ELS and Anita Catlin, DNSc, FNP, FAAN (editing) and Marie Walter, MS, RN, CPLC (content).

June 2017

## Trends in Pediatric Palliative Care Citation List and Commentary

2018; #3



*This citation list and commentary are generated monthly by PedPalASCNET to collect new articles in pediatric palliative care research. To see past citation lists and expert commentaries [visit our website](#).*

**By Khaliah A. Johnson, MD** (Attending Physician, Pediatric Palliative Care, Children's Healthcare of Atlanta, USA)

**Featured Article:** Lindley, L. C. & Newnam, K. M. (2017), '[Hospice Use for Infants With Life-Threatening Health Conditions, 2007 to 2010](#)', J Pediatr Health Care 31(1), 96–103.

**Other Feature Article:** Brock, K. E. & Mullaney, E. (2018), '[High-risk communication at the time of hospice enrollment: Standardizing pediatric hospital to hospice sign out](#)', Pediatr Blood Cancer

In reviewing the list of citations for the month of February, I was most struck by the breadth of work examining the experiences of children and families facing life-limiting, life-threatening illness across the age and disease spectrum. Palliative care experts note how important it is for services to be introduced upon diagnosis and to ideally continue throughout the disease trajectory. However, I believe we might actually be at the cusp of research reflecting what we have intuitively and anecdotally known to be true about the impact of our work. As we find increasing evidence for the value of palliative care in all pediatric age groups with a multitude of diagnoses and disorders, we must continue to examine ways to ensure that high-quality, comprehensive palliative care can be delivered to diverse populations, in a variety of practice settings.

To this end, there is growing emphasis on the importance of and need for community-based palliative care. I believe this need is particularly true for children with life-threatening illness; children's growth, development, and overall well-being are integrally linked to their experience of community. In turn, how they navigate through illness and attain quality of life cannot be separated from what happens at home, at school, and in other supportive community-based settings (such as church or even the primary pediatrician's office). In the last 5 years I have spent at Children's Healthcare of Atlanta (CHOA), I have worked with colleagues throughout the state to explore the role of hospice and other community-based services in supporting children and families with life-threatening illness. Collaborative efforts between our inpatient palliative care team at CHOA and independent hospice organizations has allowed for improved continuity of care from hospital to home, increased confidence amongst hospice providers in caring for children, and improvement of state-wide policies and procedures around access to hospice care for children and families despite their treatment preferences. While we have clearly seen the benefits of partnering with hospice in our practice setting, the articles published by [LC Lindley and KM Newman](#), and [K Brock and E Mullaney](#) remind me of gaps that still exist in ensuring for optimal utilization of pediatric hospice care.

In their study, [Lindley and Newnam](#) used a conceptual framework to examine the association between infant and family factors and use of hospice services in California Medicaid patients between 2007 and 2010. They found that of all infants who died during that time frame, 15% were enrolled in hospice services (with an average length of stay of 5 days) despite approximately 80% having access to hospice within their geographic region. In turn, infants with congenital anomalies were more likely to use hospice services than infants with cardiovascular or respiratory conditions, which might suggest a bias in referrals made from hospital to community hospice. This study highlights the importance of pursuing research to understand clinicians' referral practices and factors that impact families' receptivity to hospice.



### 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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

[Brock and Mullaney](#) highlight the importance of stream-lined communication and collaborative care in supporting pediatric oncology patients referred into hospice services from the hospital setting. Their proposal of a check-list based approach to sign-out can assist inpatient providers in thinking through the practical medical and psychosocial elements of the home care plan and support hospices in understanding the intricate details of care that often link back to patients' medical homes within oncology. [Brock and Mullaney's commentary](#) is a poignant reminder that exceptional comprehensive care of patients with serious, complex illness does not exist within a silo. We should all be thoughtful of strategies that can be leveraged to improve continuity of care for this fragile population.

I look forward to the day when every child and family has access to high quality hospice and palliative care, wherever they are. In the meantime, I remain thankful that "we're on the cusp, on the brink of enormous change."

### Citation List

- Addison, C. & Hempton, C. (2018), '[Reframing Fantasy: Toward a Common Language of Hope, Dying, and Death in Long-Shot Pediatrics](#)', *Am J Bioeth* 18(1), 36--38.
- Andriessen, K.; Mowll, J.; Lobb, E.; Draper, B.; Dudley, M. & Mitchell, P. B. (2018), '["Don't bother about me". The grief and mental health of bereaved adolescents](#)', *Death Stud*.
- Bakbakhi, D.; Siassakos, D.; Storey, C.; Heazell, A.; Lynch, M.; Timlin, L. & Burden, C. (2018), '[PARENTS 2 study protocol: pilot of Parents' Active Role and Engagement in the review of Their Stillbirth/perinatal death](#)', *BMJ Open* 8(1), e020164.
- Bally, J. M. G.; Smith, N. R.; Holtlander, L.; Duncan, V.; Hodgson-Viden, H.; Mpfu, C. & Zimmer, M. (2018), '[A Metasynthesis: Uncovering What Is Known About the Experiences of Families With Children Who Have Life-limiting and Life-threatening Illnesses](#)', *J Pediatr Nurs* 38, 88--98.
- Brock, K. E. & Mullaney, E. (2018), '[High-risk communication at the time of hospice enrollment: Standardizing pediatric hospital to hospice sign out](#)', *Pediatr Blood Cancer*.
- Cantwell-Bartl, A. (2018), '[The grief and coping of parents whose child has a constant life-threatening disability, hypoplastic left heart syndrome with reference to the dual process model](#)', *Death Stud*.
- Dereddy, N. R.; Pivnick, E. K.; Upadhyay, K.; Dhanireddy, R. & Talati, A. J. (2017), '[Neonatal Hospital Course and Outcomes of Live-born Infants with Trisomy 18 at Two Tertiary Care Centers in the United States](#)', *Am J Perinatol* 34(3), 270--275.
- Eduard Verhagen, A. A. (2018), '[Nurturing Futility in the NICU: The Dutch Perspective](#)', *Perspect Biol Med* 60(3), 449--455.
- Falkenburg, J. L.; Tibboel, D.; Ganzevoort, R. R.; Gischler, S. J. & van Dijk, M. (2018), '[The Importance of Parental Connectedness and Relationships With Healthcare Professionals in End-of-Life Care in the PICU](#)', *Pediatr Crit Care Med*.
- Fuhrer, M. (2017), '[Neurological palliative care in children](#)', *Journal of the Neurological Sciences Conference, 23rd World Congress of Neurology, WCN 2017. Japan. 381 (Supplement 1) (pp 20)*.
- Garcia-Salido, A. & Martino-Alba, R. (2018), '[The clock: Not a question of time](#)', *Palliat Support Care*, 1--2.
- Griese, B.; Burns, M. & Farro, S. A. (2018), '[Pathfinders: Promoting healthy adjustment in bereaved children and families](#)', *Death Stud*, 1--9.
- Hancock, H. S.; Pituch, K.; Uzark, K.; Bhat, P.; Fifer, C.; Silveira, M.; Yu, S.; Welch, S.; Donohue, J.;



### 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](http://www.nhpco.org/pediatrics)

- Lowery, R. & Aiyagari, R. (2018), '[A randomised trial of early palliative care for maternal stress in infants prenatally diagnosed with single-ventricle heart disease](#)', *Cardiol Young*, 1--10.
- Hanlon, P.; Guerin, S. & Kiernan, G. (2018), '[Reflections on the development of a therapeutic recreation-based bereavement camp for families whose child has died from serious illness](#)', *Death Stud*.
- Ihle, E. C. (2017), '[Enhancing resilience in hospitalized children and adolescents](#)', *Journal of the American Academy of Child and Adolescent Psychiatry Conference, 64th Annual Meeting American Academy of Child and Adolescent Psychiatry, AACAP 2017*. United States. 56 (10) (pp S16).
- Ihle, E. C. (2017), '[Posttraumatic growth in hospitalized children and adolescents](#)', *Journal of the American Academy of Child and Adolescent Psychiatry Conference, 64th Annual Meeting American Academy of Child and Adolescent Psychiatry, AACAP 2017*. United States. 56 (10) (pp S306).
- Jericho, B. G. (2018), '[Withdrawal of life-sustaining therapy](#)', *Curr Opin Anaesthesiol*.
- Lindley, L. C. & Newnam, K. M. (2017), '[Hospice Use for Infants With Life-Threatening Health Conditions, 2007 to 2010](#)', *J Pediatr Health Care* 31(1), 96--103.
- Lona Reyes, J. C.; Perez Ramirez, R. O.; Llamas Ramos, L.; Gomez Ruiz, L. M.; Benitez Vazquez, E. A. & Rodriguez Patino, V. (2018), '[Neonatal mortality and associated factors in newborn infants admitted to a Neonatal Care Unit](#)', *Arch Argent Pediatr* 116(1), 42--48.
- Martini P, Alluin R, Vieux R. [Palliative care in neonatology: French neonatologists' practice](#). *Medicine Palliative*. 2017 Dec;16(6):293--301.
- Meyer, D.; Schmidt, P.; Zernikow, B. & Wager, J. (2018), '[It's All About Communication: A Mixed-Methods Approach to Collaboration Between Volunteers and Staff in Pediatric Palliative Care](#)', *Am J Hosp Palliat Care*, 1049909117751419.
- Mitchell, S.; Slowther, A. M.; Coad, J. & Dale, J. (2018), '[The journey through care: study protocol for a longitudinal qualitative interview study to investigate the healthcare experiences and preferences of children and young people with life-limiting and life-threatening conditions and their families in the West Midlands, UK](#)', *BMJ Open* 8(1), e018266.
- Nambayan, A. G. (2018), '[Palliative Care: Opportunities for Nursing](#)' *Asia Pac J Oncol Nurs*, pp. 1--3.
- Nuzum, D.; Meaney, S. & O'Donoghue, K. (2018), '[The impact of stillbirth on bereaved parents: A qualitative study](#)', *PLoS One* 13(1), e0191635.
- Ockelford, A. & Atkinson, R. (2017), '[Neurodegenerative conditions: Exploring the role of music to enhance speech and cognitive functioning in children with batten disease](#)', *Developmental Medicine and Child Neurology Conference, 44th Annual Conference of the British Paediatric Neurology Association, BPNA 2018*. United Kingdom. 59 (Supplement 4) (pp 76--77).
- Pearson, G. A. (2018), '[Intensive care: because we can or because we should?](#)', *Arch Dis Child*.
- Peng, N. H.; Lee, C. H.; Lee, M. C.; Huang, L. C.; Chang, Y. C. & DeSwarte-Wallace, J. (2017), '[Effectiveness of Pediatric Palliative Care Education on Pediatric Clinicians](#)', *West J Nurs Res* 39(12), 1624--1638.
- Pieper, L.; Zernikow, B.; Drake, R.; Frosch, M.; Printz, M. & Wager, J. (2018), '[Dyspnea in Children with Life-Threatening and Life-Limiting Complex Chronic Conditions](#)', *J Palliat Med*.
- Short, S. R.; Poynter-Wong, S. & Flint, H. (2018), '[Pccm fellows' palliative care knowledge and attitudes](#)



### 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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

- [surrounding a pilot educational initiative](#)', *Critical Care Medicine* Conference, 47th Society of Critical Care Medicine Critical Care Congress, SCCM 2018. United States. 46 (Supplement 1) (pp 182).
- Slater, T.; Laddie, J.; Hughes, G. & Lumsden, D. E. (2017), '[Prevalence and management of dystonia in a paediatric palliative care cohort](#)', *Developmental Medicine and Child Neurology* Conference, 44th Annual Conference of the British Paediatric Neurology Association, BPNA 2018. United Kingdom. 59 (Supplement 4) (pp 11--12).
- Sullivan, J. E.; Gillam, L. H. & Monagle, P. T. (2018), '[The enactment stage of end-of-life decision-making for children](#)', *Palliat Support Care*, 1--7.
- Turner, D.; Schwartz, A.; Carraccio, C.; Herman, B. & Mink, R. (2018), '[Using entrustable professional activities to assess graduation readiness in pediatric critical care](#)', *Critical Care Medicine* Conference, 47th Society of Critical Care Medicine Critical Care Congress, SCCM 2018. United States. 46 (Supplement 1) (pp 188).
- Verhagen, A. A. E. (2018), '[Teamwork and conflicts in paediatric end-of-life care](#)', *Acta Paediatrica, International Journal of Paediatrics* 107(2), 192--193.
- Warlow, T. A. & Hain, R. D. W. (2018), '["Total Pain" in Children with Severe Neurological Impairment](#)', *Children (Basel)* 5(1).
- Weekly, T.; Walker, N.; Beck, J.; Akers, S. & Weaver, M. (2018), '[A Review of Apps for Calming, Relaxation, and Mindfulness Interventions for Pediatric Palliative Care Patients](#)', *Children (Basel)* 5(2).
- Weiss, E. M. & Fiester, A. (2018), '[From "Longshot" to "Fantasy": Obligations to Pediatric Patients and Families When Last-Ditch Medical Efforts Fail](#)', *Am J Bioeth* 18(1), 3--11.
- Yazde Puleio, M. L.; Gomez, K. V.; Majdalani, A.; Pigliapoco, V. & Santos Chocler, G. (2018), '[Opioid treatment for mixed pain in pediatric patients assisted by the Palliative Care team. Five years of experience](#)', *Arch Argent Pediatr* 116(1), 62--64.

-###-



### 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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

## ITEMS OF INTEREST

In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

### 1. **NHPCO Palliative Care Online Resources:**

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

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

### **Palliative Care Programs and Professionals**

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

[Individual Palliative Care Membership](#)

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

### 2. **Pediatric Hospice and Palliative Care Resources:**

- **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. [www.caringinfo.org](http://www.caringinfo.org)
  - *When Your Child is in Pain*
  - *Talking With Your Child About His or Her Illness*
  - *Talking to Your Child's Doctor: When Your Child Has a Serious Illness*
  - *When a Child Dies: A Guide for Family and Friends*
  - *Helping Children Cope with the Loss of a Loved One*
- **NHPCO's Palliative Care Resource Series** now includes pediatric palliative resources such as:
  - *Communication Between Parents and Health Care Professionals Enhances Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy*
  - *Consideration for Complex Pediatric Palliative Care Discharges*
  - *'Who You Gonna Call?' Men with Duchenne Muscular Dystrophy Discuss End-of-life Planning*
  - *Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and Hospice Care*
  - *Nonpharmacological Pain Management for Children*
  - *Sibling Grief*
  - *Pediatric Pain Management Strategies*
  - *Communicating with a Child Experiencing The Death of a Loved One: Developmental Considerations*
- **Center to Advance Palliative Care:** Did you know there are new tools to support your program? CAPC is pleased to announce the launch of three new resources for pediatric programs.
  - [Pediatric Palliative Care Survey in the CAPC National Registry](#): Submit your program data now to generate individualized performance reports on program structure and operations, as well as comparisons to other pediatric palliative care programs. CAPC membership is not required.



#### **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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)



- [The Pediatric Palliative Care Field Guide](#): A catalog of field-wide program development tools, support sources for field research, and an updated value statement to help programs make the case for pediatric palliative care resources.
  - [The CAPC Pediatric Palliative Care Toolkit](#): A collection of new, practical tools and technical assistance for pediatric palliative care programs developed by leaders and experts across the country. Available to members now in CAPC Central.
- “A Perinatal Pathway for Babies with Palliative Care Needs” from Together for Short Lives in the U.K., developed in conjunction with ethicists and clinicians working across obstetrics, antenatal and neonatal care, and children’s palliative care. Full pathway available for free download via this press release and links here: [http://www.togetherforshortlives.org.uk/news/11605\\_together\\_for\\_short\\_lives\\_launches\\_vital\\_resource](http://www.togetherforshortlives.org.uk/news/11605_together_for_short_lives_launches_vital_resource)
  - Three Years ago Holland Bloorview Kids Rehabilitation Hospital launched [the Chronic Pain Assessment Toolbox for Children with Disabilities](#). The Toolbox has received over 6000 downloads to date! Since then three eLearning modules have been developed. The modules will introduce you to:
    1. Chronic pain in children with cerebral palsy and the development of the Toolbox
    2. The sections of the Toolbox and how to start with based on your needs
    3. A case study of a complex patient from one of our nurse practitioners, and how a chronic pain assessment tool supported her clinical examination.

Check them out here: <http://hollandbloorview.ca/Toolbox>

### 3. Pediatric Hospice and Palliative Care Training:

- The Hospice and Palliative Credentialing Center (HPCC) is conducting a role delineation study (job analysis) to update the Certified Hospice and Palliative Pediatric Nurse (CHPPN) exam specifications. An online survey will be used to identify critical tasks performed by nurses who provide care to children (i.e., perinatal period, infancy, childhood, adolescence, and young adulthood) facing serious and potentially life-limiting illnesses. Results from this survey will be used to ensure that CHPPN exam content reflects current practice of pediatric hospice and palliative care nurses.

For those of you providing pediatric palliative and hospice nursing care, we invite your participation. By completing this survey (it should take about 20 minutes), you will help promote the work of nurses who provide care to children and their families facing serious and life-limiting illnesses. Please complete the survey using your best judgment no later than May 31, 2018. To begin, click on the link below. If clicking on the link does not take you to the survey, try copying and pasting the entire link text into your browser address field and pressing enter.

<https://www.research.net/r/chppnrdsnhpco>

- **Upcoming 2018 Webinars provided by the Pediatric Care Coalition:**
  - June 19th or 20th  
**Pain & Symptom Management in Children**  
with Audrey Foster-Barber, MD-UCSF
  - September 25th  
**Transitioning Adolescents into Adult Care**  
with Parag Shah, MD and Rebecca Boudos - Lurie Children's Hospital



#### 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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

- October 18th  
**Medical Marijuana**  
with Elissa Miller, MD Nemours/Alfred I. DuPont Hospital for Children  
and Billie Winegard, MD Children's Hospital of Illinois
- November  
**Bereavement/Parent Perspectives**

- **Pediatric Hospice and Palliative Care: Advances and Innovations (Pedi-Innovate):**  
This summer pediatrics course will be a forum for interdisciplinary healthcare professionals and others with an interest in pediatric palliative care to deepen their knowledge and understanding of this nascent and rapidly-evolving field.  
Through this course, we aim to advance pediatrics in hospice and palliative care for children with serious illness, thereby optimizing their quality of life, regardless of treatment course or illness trajectory. Learners will improve their knowledge, competence, and change their performance, leading over time to enhanced patient outcomes.  
August 9-11, 2018  
Minneapolis, MN  
<http://aahpm.org/meetings/pediatrics-course>
- **NHPCO's Interdisciplinary Conference**  
Preconference Dates: November 3-4, 2018; **Expert Interdisciplinary Care for the Developing Pediatric Team**  
Main Conference Dates: November 5-7, 2018  
Hyatt Regency New Orleans, New Orleans, LA  
<https://www.nhpco.org/IDC2018>

#### 4. Journal/News Articles

- **The Long Ride Home:** "Honesty works. It is deservedly our gold standard. But perhaps even in our culture of full disclosure, there are times when we give more to families when we give them less." A perspective piece by David N. Korones, M.D. Read more [here](#)
- **New Rutgers App Seeks to Reduce Infant Mortality:** Each year, about 3,500 infants under the age of one year die in the United States due to a sudden unexpected infant death. To better educate parents and to create a more efficient way for health care providers to share information on safe sleep recommendations, Barbara Ostfeld and Thomas Hegyi of the SIDS Center of New Jersey, based at Rutgers Robert Wood Johnson Medical School and Hackensack Meridian Health, have developed the free SIDS Info app for iPhone and Android. Read more [here](#)
- **Treating childhood trauma:** Oprah Winfrey reports on how trauma plays a role in childhood development and what new methods are being used to help kids who have experienced it. Read more [here](#)

5. **Subjects and Contributors for Future Issues of This E-Journal.** For upcoming E-Journal issues, we plan to address issues related to: Hospice and Bereavement for Crisis Situations, and Caring for Diverse Families and Populations. 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 [ctorkildson@mail.cho.org](mailto:ctorkildson@mail.cho.org) or [christytork@gmail.com](mailto:christytork@gmail.com); or Chuck Corr at [ccorr32@tampabay.rr.com](mailto:ccorr32@tampabay.rr.com). We will work with you!
6. **Reader's Corner.** Our Reader's Corner columns provide brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of



#### 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](http://www.nhpco.org/pediatrics)

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](mailto:christytork@gmail.com).

-###-



**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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)