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TRAUMA AND TRAUMA-INFORMED CARE FOR PATIENTS AND FAMILIES

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Issue Topic: Trauma and Trauma-Informed Care for Patients and Families

Welcome to the 82nd issue of our Pediatric e-Journal. The focus of both this issue and the one that immediately follows is on topics that relate to trauma and trauma-informed care. This issue specifically addresses trauma and trauma-informed care as they involve patients and family members. Issue #83 will address trauma and trauma-informed care as they involve providers and care teams.

Unfortunately, trauma and the need for trauma-informed care are all too frequently encountered in pediatric hospice and palliative care. Even two issues of our e-Journal will likely not be sufficient to address these subjects in a comprehensive fashion. However, by addressing these topics in two distinct issues, we hope that the articles offered here will spark broad discussion of this important subject area.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Alliance for Care at Home (the Alliance). The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Melissa Hunt. Chuck Corr is our Senior Editor. Archived issues of this publication are available at: allianceforcareathome.org/pediatric-e-journal/

Comments about the activities of the Pediatric 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 is for Issue #84 to focus on spiritual support in pediatric hospice and palliative care. We have some ideas for Issue #85, but we are open to suggestions. If you have any thoughts about these topics or other subjects and/or potential contributors (including yourself) for future issues, please contact Christy Torkildson at Christy.Torkildson@gcu.edu or Melissa Hunt at melissa.hunt@handsofhopese.com

Views expressed in this and other issues of the Pediatric e-Journal are exclusively those of the authors and do not necessarily reflect the views of the Pediatric e-Journal Workgroup, the Pediatric Council, or the National Alliance for Care at Home.

Produced by the Pediatric e-Journal Workgroup

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Mason's Miracle

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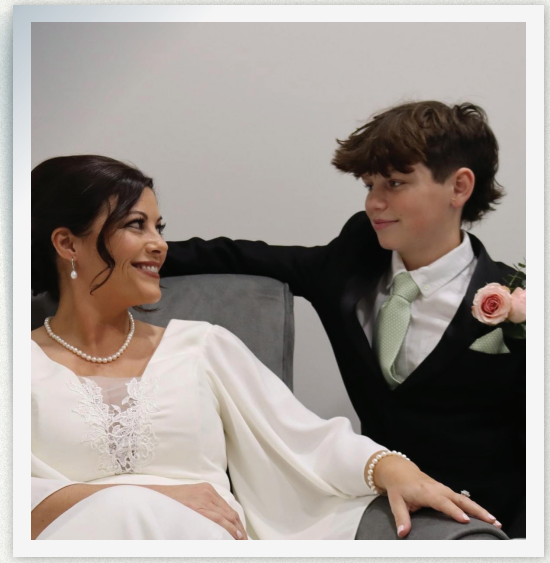
When I began my career as a Registered Nurse in the Pediatric Intensive Care Unit (PICU) at Children's Hospital New Orleans in May 1999 I never, ever imagined I would be on the other side of the room as a mom of a critically-ill patient in that same PICU. Twenty-five years later that is exactly where I found myself. How could this be happening? Is this a nightmare that I will wake up from any minute? This is not my life. I am watching someone else's life unfold before my very eyes. I felt like everything was spinning around me and I was just standing still in the middle of this whirlwind.

Mason, my youngest of 3 children, was a healthy, energetic, goofy, 14-year-old. He loved God, his family, and sports. He played football and basketball from the age of 5. He always said when he grew up he was going to be a pastor and an NFL player. He said his goal was to preach to his teammates in the locker room. He was active in our youth group, and he volunteered in the children's ministry, teaching bible lessons. He served every year at vacation bible school, and he loved going to summer camp with our youth group. He talked nonstop and never met a stranger. He was known to reach out to the quiet ones and stand up for those that were being mistreated. He loved joking around and being the center of attention. He always made people laugh and did his best to encourage and point others to the Lord. He was the biggest momma's boy and bragged that he was the favorite. He gave the best hugs, was compassionate, and was quick to apologize when he knew he was wrong.

March 31, 2024 started off like any other Sunday morning at church. It was Easter Sunday, so I made sure to snap the obligatory family picture before we left. I am forever grateful for this picture, because it would be our last family picture. About 5 hours later, my youngest son, Mason, was riding on a golf cart with friends and fell off. He hit his head and had road rash down his back. He called me asking me to pick him up because he fell and he was tired. We got home and I did all the things I thought of as a nurse and a mom. In the back of my mind I was thinking concussion so I told my husband if he began vomiting we were going to the hospital. He was completely alert and oriented. He said his head hurt. I gave him medicine for the headache and an ice pack. He asked me to take pictures of his back and text them to him. He then asked my husband and me to pray over him. We stood in our kitchen and prayed over him. Another moment that I will forever cherish. He remained



alert and oriented until he vomited then began seizing and posturing. After checking for a pulse and breathing, I opened his eyes and I knew in that moment our lives were forever changed. His eyes were fixed and dilated. I screamed and collapsed. I kept screaming, "I know what this means." We were life-flighted to Children's Hospital New Orleans. He had a brain bleed and swelling. He was taken into surgery, the bleeding was stopped, but unfortunately the damage was done. I will never forget the neurosurgeon's words to me. He said he knew I was a nurse and I understood so he wasn't going to sugarcoat anything. He said "he is a very sick boy, VERY SICK." While those words stung, I needed his honesty. The next 7 days were chaos and confusion as multiple tests were done and I just watched my sweet baby boy slip away. Medically speaking I knew the grim outlook, but as a mom and a Christian I knew that God could miraculously heal him.

The staff helped make this awful time in our lives a beautiful experience. They treated Mason like he was the only patient in the unit, when in reality he was one of 3 patients that week that were becoming organ donors. I know firsthand how emotionally taxing that is on the staff. They spoke to him so lovingly and explained what they were doing. I know he could hear everything we all were saying to him until the very end. The doctors were so patient and accommodating, explaining things over and over to our extremely large family. The PICU attending took time to talk one-on-one with my daughter, something that I know she will never forget. They allowed us time to pray and worship all together as a family. They shared their faith openly with us and made us all feel so loved. Mason and our family weren't just a patient, we were family. The child life department met with Mason's friends before they saw him to prepare them for what they were going to see and they were available for questions if needed throughout the visit. All these things that may seem like just a normal part of each person's job but they mean more to a family member going through a crisis than anyone will ever realize.

About 6 months before his accident Mason asked why I had a red heart on my driver's license. I told him that meant I was a registered organ donor. We discussed the meaning of organ donation and without hesitation he looked at me and said, "Oh mom when I die I definitely want to donate my organs." Then 3 months later he and my husband went hunting. We didn't realize until months after he passed that he was registered to be an organ donor when he got his hunting license. I never imagined that just months after these two events I would be faced with the heartbreaking decision of donating his organs.

I knew about organ donation from the age of 16. My stepsister passed away and was an organ donor. I registered to be a donor when I got my driver's license. I had a passion for taking care of the patients in the PICU that became donors. I enjoyed working alongside the staff of LOPA—Louisiana

Organ Procurement Agency—and I was drawn to these families during their darkest, hardest times. Then here I was—one of those families.

Mason passed away on April 7, 2025, and through the miracle of organ, tissue, and cornea donation he saved 5 people, gave sight to 2, and enhanced the lives of many through tissue donation. There is nothing that takes the pain away, but it helps me in this journey knowing that he lives on through others. I've had the pleasure to meet his liver recipient in person, and I've received a letter from one of his kidney recipients. The community of other donor families, recipients, LOPA, and Southern Eye Bank staff that I have met along the way have become like family to me. I've also had the privilege of volunteering with both agencies and sharing our story. Each time I help raise awareness and educate on organ donation I feel like Mason is with me, cheering me on. I feel like my heart is being put back together piece by piece, never the same, never whole again, but restored. I would never survive even one minute of this new life without God holding me and carrying me each step of the way. He promises he will never leave nor forsake me, and He is right by my side. "The Lord is near to the brokenhearted and saves the crushed in spirit." ***Psalm 34:18***

I've been told so many times in this last 18 months "you're so strong." The strength you see is not my own. It comes from God. "But he said to me, 'My grace is sufficient for you, for my power is made perfect in weakness.' Therefore I will boast all the more gladly of my weaknesses, so that the power of Christ may rest upon me." ***2 Corinthians 12:9.*** I've found comfort and support from other bereaved parents, and it has ignited a passion in me to pay it forward. My husband and I have started the New Orleans chapter of While We're Waiting—Support for Bereaved Parents. There are no words that will take the pain away from a parent that has lost a child. There is no fixing us. However, there is hope and His name is Jesus. There is comfort when we walk this life in community, together, with our eyes on Jesus. "He comforts us in all our troubles. So that we can comfort others. When they are troubled, we will be able to give them the same comfort God has given us." ***2 Corinthians 1:4***

If I could end this with a few things I have learned along the way, some advice if you will, it would be never take one second of this life for granted. The things of this world are temporary. If you don't have a strong foundation of faith in Jesus please make that decision today to accept Jesus as your savior. Seek Him, draw near to Him and He will draw near to you. Storms will come in life—it's not if, but when—God tells us "in this world we WILL have trouble, but take heart I have overcome the world." A life-shattering event like losing a loved one is too much for anyone to handle alone. We were made to live in community. This world is not our home, heaven is our home. Our present troubles will not last forever. To the medical community I would like to say thank you. Thank you for taking such good care of my boy and our entire family. On the hard days remember why you chose this profession. It is OK to be honest and vulnerable with your patients and their families. You don't

have to have the perfect words to say, because sometimes there are no words. Cry with them, laugh with them, grieve with them, and celebrate with them. At the end of the day those encounters will change their life and yours.

I don't know what the future holds for me and my family. There are many days I feel like I can't take another step, and many days I just want to scream because I just want my boy back in my arms. Since that will not happen this side of heaven I have a choice to make—am I going to let God turn my pain into purpose or am I going to let the enemy keep me down? I know Mason would not want that for me, so until I see him again in heaven I will Live Like Mason Kiley (LLMK)—sharing my faith, sharing his story, sharing my pain, and sharing the hope and encouragement that I've found along the way.

Learning to Navigate Trauma-Informed Care

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My son Kevon was diagnosed with a rare genetic condition, SPTAN1 gene mutation, at just six months old. While a diagnosis can offer a name for what is happening, it does not always provide answers or prepare a family for what lies ahead. Shortly after his diagnosis, Kevon went into respiratory failure, resulting in a seven-month stay at Seattle Children's Hospital.

During that time, our family faced an unimaginable decision: keep Kevon comfortable or proceed with a tracheostomy. Choosing the tracheostomy meant giving him a chance at life. That choice also meant learning, very quickly, how to reshape our lives to meet his complex medical needs while still allowing him to experience joy, connection, and growth.

Today, Kevon is eight years old and doing well. He is the middle child between an older sister who is ten and a younger brother who is five. Over the years, we have learned an important lesson: having a medically complex child does not mean that life must be traumatic all the time.

Our family has learned to navigate care through a trauma-informed lens by focusing on three key practices: humanizing the care team, including our children in Kevon's care, and intentionally highlighting positive moments through photo narratives.

Navigating a healthcare system filled with specialists can be intimidating. First impressions matter. When providers or caregivers enter a room with a "know-it-all" attitude, it can create distance and make families hesitant to ask questions. Something as simple as beginning a visit with "How are you doing?" can change the tone of the entire interaction. Getting to know the family before caring for them is just as important as families getting to know their providers. Mutual respect and connection build trust, which is essential in long-term care relationships.

Including Kevon's siblings in his care has shaped our family. It has taught them compassion, responsibility, and awareness. During family outings, they help ensure Kevon is safe—making sure he is buckled in properly or secure when we stop. We approach these moments with intention, making

them both educational and fun, allowing our children to experience the world through Kevon's perspective.

As a family, we experience both the challenges and the victories together. Capturing positive moments through photos has become a powerful tool for healing. Looking back on these images reminds us of joy, resilience, and connection beyond hospital rooms and medical equipment. Sharing these photos with Kevon's providers has also opened doors for deeper relationships, allowing them to see him—and us—as more than a diagnosis.

Through connection, inclusion, and intentional positivity, our family has learned that trauma-informed care is not just a clinical approach—it is a human one.

Seeing Families, Not Just Patients: A Mother's Perspective on Trauma-Informed Care

FROM A MOTHER AND TRAUMA-CERTIFIED COACH

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As I stared out the hospital window, I wanted to escape.

My first thought was somewhere tropical, warm, quiet, far away from the devastation I was carrying in my womb. Just a week earlier, we had been told our son, Hudson, had hypoplastic left heart syndrome and would need multiple surgeries for a chance at life. Then more news came. More complications. More uncertainty. I wanted to run.

But reality settled in quickly. No matter where I went, Hudson was coming with me, and so was his diagnosis. His kicks reminded me constantly of his presence and our pain. There was nowhere to hide.

What I could not escape was the hospital itself: the required medical care, nearly a year of inpatient stays, and eventually losing Hudson after his second open-heart surgery. I also couldn't escape the overwhelming love I had for him, a love that still shows up today as grief, tears, and longing.

I share this as Hudson's mom and as someone who has spent years learning how trauma lives in the body, shapes decision-making, and influences how people cope, connect, and heal. What I understand today comes from living this story and learning how to make sense of it.

When the place of healing becomes part of the trauma

Hospitals save lives. They also, often unintentionally, become places where trauma takes root.

For families like ours, the hospital held some of the most terrifying moments of our lives. The alarms. The procedures. The endless decisions. The lack of sleep. The constant sense that everything

mattered and nothing was in our control. These experiences don't disappear when the crisis ends. They live on in the body long after discharge or death.

Trauma is not only about what happens to us. It is about what happens inside us when we feel overwhelmed, unsafe, powerless, or unseen.

Where we felt seen and safe

Amid all of this, there were moments of profound care that made a lasting difference.

Through countless prenatal appointments, procedures, and months inpatient with Hudson, we experienced care that was deeply human and trauma-aware. Nurses and doctors called us by name. They knew the smallest details about Hudson, and not just his diagnosis, but who he was. They asked about his two-year-old big brother. They remembered what mattered to us.

They cried with us.

Hudson was treated as a baby first and a patient second. That distinction mattered more than anyone could have explained at the time. When we felt seen as people, not just participants in a care plan, our nervous systems softened. Trust grew. We could breathe.

Lessons from the bedside

There were also moments that stayed with us in a different way.

It likely felt like just another day on the floor for staff, while for us it was a moment that would permanently shape our lives. Sometimes it was not being heard when I knew something wasn't right. Once, when two medications were weaned at the same time, it dangerously elevated Hudson's heart rate. My concern wasn't emotional; it was informed by knowing my child.

There were times when the information we were given was incredibly heavy, delivered in settings that felt formal and clinical. In those moments, additional emotional or spiritual support could have made a meaningful difference as we tried to absorb life-altering news.

These moments taught me something important: tone matters. Presence matters. Touch matters. Compassion is not an extra. It is part of good and thorough care.

Trauma responses are not character flaws

In high-stress medical environments, it's easy to interpret behavior at face value. Trauma-informed care asks us to look deeper.

A trauma response is not just emotional; it is physiological. Breathing changes. Heart rate increases. Thinking narrows. Processing slows. Responses may seem irrational, intense, or inconsistent, but they are rooted in survival, not defiance.

Anger. Overwhelm. Withdrawal. Shutdown. Appearing "uncooperative." Staying constantly at the bedside or barely visiting at all. These are often trauma responses, not reflections of character, motivation, or love.

Trauma-informed care asks us to slow down and wonder what someone may have lived through, rather than reacting to how they are showing up.

Borrowing your nervous system

One of the most powerful tools you bring into any medical interaction is your regulated presence.

Staying calm does not mean staying detached. Calm can be warm, steady, and connected. Like a parent holding steady while a toddler melts down, your nervous system can offer safety when others cannot find it on their own.

Trauma trains the nervous system to constantly scan for danger and keeps people in a state of high alert or shutdown. Your tone, pacing, body language, and presence can communicate safety long before words are fully heard.

Collaboration and choice restore the feeling of safety

Trauma takes away a sense of control. Trauma-informed care restores it wherever possible.

Include parents and patients in decisions, even small ones. Don't hide information to try to protect them. Transparency builds trust. When people understand what is happening, their nervous systems can settle.

Where choice exists, offer it. Listen fully. Hear concerns without defensiveness. Giving families a voice helps restore dignity and agency in moments where so much feels powerless.

Asking the questions that matter

Even when you don't know the full story of a patient or family, approach them with the assumption that past trauma may be present and that it may be activated in this moment of medical care.

Simple questions can be grounding:

"What feels most overwhelming right now?"

"What would feel supportive in this moment?"

"Is there anything you want us to know about your child or your family?"

You don't need perfect language. You need curiosity without judgment.

Why trauma-informed care matters

Because it changes outcomes.

When people feel safe, they engage more fully in care. They ask questions. They participate in decisions. They trust the team around them. Trauma-informed care helps people feel safe enough to stay engaged, ask questions, and keep going, especially when they're already carrying loss, medical trauma, or long-term stress.

This is not extra training. It is effective medicine.

Trauma-informed care in death and grief

When a child dies, grief and trauma intertwine.

In these moments, advice-giving, premature closure, or well-intended statements that minimize loss can re-activate trauma. Families don't need explanations. They need steady presence.

What helped us and continues to matter:

Personal notes from those who cared for Hudson

A clip of his hair and a mold of his hand

Treating him as a baby, not just a patient

Honoring his life, not rushing past his death

If you can't personally relate, don't try to. Presence is enough.

What to say and what not to say

Helpful:

"I'm so sorry."

"He matters."

"I will remember him."

"You don't have to do this alone."

Harmful:

“At least…”

“Everything happens for a reason.”

“You’re so strong.”

“I could never live through something like this.”

Anything that explains away pain instead of acknowledging it.

Ten years later

There are still days I wish I could escape the pain of not having Hudson here with our family. What has changed is my ability to meet those waves with more steadiness and to recognize what my body needs in moments of grief and dysregulation.

The trauma of nearly a year in the hospital and then losing Hudson still exists. And so does the healing that is shaped by education, practical tools, faith, and the care we received from teams who treated Hudson and our family with dignity.

Just recently, I was cleaning out a box of Hudson’s things in the garage. My husband came outside to find me in a pool of tears.

“Why is it still so hard after all these years?” I asked.

Then, through his own tears, he said, “I’m so sorry, baby. We still love him.”

And that is why it is still so hard. We still love him.

Thank you to every doctor, nurse, and hospital staff member who walks alongside families through the unimaginable. Your presence matters more than you may ever know.

Trauma-Informed Care: Lily's Journey

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Children and families facing end-of-life situations often carry layers of trauma—medical, emotional, and relational—that shape how they engage with care. Trauma-Informed Care can be a useful skill when working with impacted families. While trauma can be defined in various ways, experiences first-hand or second-hand, within the scope of pediatric hospice clinicians, adopting a trauma-informed lens can strengthen compassion, build trust, and reduce distress at a time when families need it the most.

I still remember the day I met Lily. This tiny little girl, with BIG fears! Lily was an 8-year-old living with cystic fibrosis. She had endured multiple tests and procedures over the years resulting in an intense fear of medical offices, hospitals, and medical professionals. Lily would fight, scream, cry anytime she needed a blood draw or port access. Her parents initially sought counseling due to regression and meltdowns at home and school. Lily's parents hadn't yet made the connection between the medical trauma and the behaviors. Lily's mom shared, "I don't understand what is wrong with her." I posed an alternate question: "Maybe there isn't anything wrong with her, maybe it's what happened to her that has shaped her behaviors."

Trauma-Informed theories shift the question from "What is wrong with the child?" to "What has happened, and what do they need to feel safe and supported?" This perspective helps us understand children's behaviors, parental emotions, and family dynamics through a trauma-sensitive lens. How many times have we had parents report their children's behavior as disruptive and seeking a "solution" to correct the behavior? With a Trauma-Informed lens we would first seek to understand the "why" behind the behavior.

Children may show trauma responses such as regression, irritability, hypervigilance, avoidance of medical staff, or intense fear during routine care. Their emotional bandwidth may be limited, especially if illness has reduced their ability to communicate or process experiences. Imagine, having multiple "sticks and pokes," seeing your bright red blood running through tubes, being held down when you resist, all before the age of 8 years old. I don't know about you, but my anxiety went up just thinking about it. Parents and caregivers, meanwhile, may express their trauma through hyper-controlling behaviors, emotional numbness, difficulty absorbing medical information, irritability, guilt, or mistrust.

Lily presented with symptoms similar to Post Traumatic Stress related to her medical trauma-hypervigilance, nightmares, avoidance, regressive behaviors, and mood changes. Lily would describe

nightmares consisting of "people holding me down and taking my blood" or being chased by needles. She would have to be "dragged" into buildings or off elevators for medical appointments and would have episodes similar to panic attacks just pulling into the hospital parking lot. Trauma can emerge from multiple sources, especially in pediatric medical settings. Many children have endured chronic medical trauma through years of hospitalizations, invasive procedures, sudden exacerbations, and moments of intense fear.

Substance Abuse and Mental Health Service Association (SAMHSA) has created guidance for a trauma-informed approach to care (2014). The core principles, include: Safety; Trustworthiness and Transparency; Collaboration and Mutuality; Empowerment, Voice, and Choice; Peer Support; and Cultural, Historical, and Gender Issues. Trauma-informed skills are not only important for mental health professionals, it is an important skillset for anyone who cares for children—medical professionals, first responders, teachers, daycare workers, law enforcement, etc.

Creating a sense of safety; physical, emotional, and relational is the first step. I needed to create predictable interactions, provide gentle transitions, and reassurance. I ensured Lily knew what to expect during each visit. We developed a routine for each session together with a start and a clear ending (which was always a snack). Lily struggled with transitions, so we utilized a session timer that she set at the beginning of each session that gave her a 10-minute warning for the end of session. I also worked with the family to identify any upcoming appointments so I could prepare Lily for what to expect will happen during visits, procedures. What would Lily see? What would Lily hear? What would Lily smell? What would Lily feel?

Lily also needed to build trust. She did not trust me at first. Why should she? Everyone else who claimed to "help" in her eyes only "hurt" her. Clear and honest communication, consistent follow through, and explaining the "why" behind steps help reduce anxiety. Every session started with clear explanation of what we were going to do and also giving her an opportunity to pick an activity to provide her with a sense of control. Trauma-informed approaches, such as explaining each step, using comforting tones, and asking permission, all help children feel seen and safe. Even simple gestures like offering choices or acknowledging fear can significantly reduce distress.

Parents are the experts on their child. Trauma-informed care emphasizes shared decision-making, respecting family intuition and cultural values, and working alongside families rather than directing them. This reduces power imbalances and reinforces dignity. Lily's parents were involved in every step and participated in several conjoint sessions to help model and practice intervention skills. By teaching the parents that Lily's behaviors were a result of her experiences rather than just behavior issues they were able to better understand her fears and reactions.

In medical situations children often feel powerless. But offering choice can be healing: choosing when to discuss sensitive topics, how to arrange care, or which rituals or memory-making activities matter most. Small choices for children, such as choosing a comfort object or deciding the order of a procedure, also support autonomy and emotional regulation. To help Lily feel "protected" during medical procedures we created a Safety Wrap that she could drape around herself during scary procedures. The wrap was decorated in session with positive images, sayings, colors, and most

importantly “charged” by being hugged by her mom before she draped around herself. Lily called her wrap her “Super Cape” that had powers to protect her.

While I couldn’t always be present for Lily’s procedures, I provided the parents the language to empower them to advocate for their child. Repeated procedures or past painful experiences can create strong associations between clinicians and fear. Trauma-informed care mitigates this by suggesting child-friendly language (“Your body might feel a squeeze”) and slowing down to observe a child’s cues. When children feel respected rather than rushed or overwhelmed, they are less likely to experience re-traumatization. Lily was also taught relaxation techniques to help reduce stress and avoid triggering distressing emotions. Breathing techniques such as cookie breathing—pretend you are holding a cookie, then smell it (4 seconds), then blow on it because it is too hot (4 seconds). Grounding exercises such as “I spy” where Lily would look for anything in the room that was blue (her favorite color) helped shift her focus and attention.

Ultimately, Lily was able to heal from most of her medical trauma and learn to trust her medical professionals. She was given tools to help relax and tools to create a sense of safety. Lily’s parents were taught how to support Lily when she was feeling anxious, prepare her for procedures, and be empowered to advocate for her during appointments.

Trauma-Informed Care is compassionate, dignified, family-centered support. By recognizing trauma’s impact and responding with sensitivity, clinicians can reduce distress, build trust, and promote meaningful connection during a profoundly vulnerable chapter in a family’s life. Trauma-Informed Care allows children to experience comfort, respect, and dignity, while giving families a sense of safety and empowerment that can shape their healing.

When Behavior is a Story: Recognizing Trauma Responses in Children and Ways to Support Them & Their Families

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Trauma is an often unseen but ever-present force in pediatric care, shaping not only the experiences of medically complex children but their families and the providers who support them. What presents as a "behavior," or moments of resistance or emotional intensity, is frequently the nervous system's attempt to survive overwhelming stress, uncertainty, and loss of control. At the same time, siblings and caregivers absorb the ripple effects of medical trauma in ways that are often quiet, cumulative, and profound. This article explores how trauma can manifest through behavior, relationships, and family systems, as well as how trauma-informed care offers providers a powerful pathway toward deeper understanding, improved outcomes, and sustainable healing for children, families, and care teams.

Behaviors are a child's first forms of communication. In pediatric care, this can look like "negative behaviors," such as resistance, avoidance, aggression, or shutdown. Yet these behaviors are rarely random. For children with medical complexity, chronic illness, or developmental differences, behavior frequently reflects an overwhelmed nervous system shaped by repeated stress, pain, and feeling the loss of control. What may look like acting out, defiance, or noncompliance is often time a survival response, or a child's way of communicating distress, which can often get overlooked or misinterpreted.

Children exposed to medical trauma often experience their world as unpredictable and threatening. Repeated hospitalizations, invasive procedures, sensory overload, separation from caregivers, and emergency situations teach the nervous system to almost constantly anticipate danger. Over time, survival responses become automatic. The brain no longer pauses to evaluate safety; it starts to just assume threat as the default. This shift profoundly impacts how children approach caregivers, providers, and even their own bodies.

For children, their developing nervous systems are exquisitely sensitive to threat. When safety is compromised, the body moves instinctively into fight, flight, freeze, or fawn. A child may hit, try to run, shut down, or comply rigidly without emotional engagement. These reactions are not willful misbehavior. They are biological attempts at protection. Children with developmental delays, autism,

or limited verbal skills are particularly vulnerable because they often lack the language to adequately communicate or explain fear or discomfort. Their behavior becomes their form of communication.

In everyday practice, trauma responses often present in subtle but powerful ways. A toddler may thrash during diaper changes. A school-aged child may refuse to enter an exam room. An adolescent may dissociate, becoming distant and disconnected during procedures. These behaviors can appear disproportionate to the task at hand, leading parents and/or providers to feel confused or frustrated. Yet for the child, the body is responding not just to the present moment, but to accumulated memories stored in the nervous system.

Traditional behavioral approaches that rely on compliance, repetition, or restraint often escalate rather than resolve distress. When a child's nervous system is activated, their "thinking brain" or their capacity for reasoning, cooperation, and learning temporarily shuts down. Attempting to force compliance in that state can deepen fear and reinforce trauma. Trauma-informed care instead begins with curiosity. Providers can ask themselves: What is this behavior protecting? What threat is the nervous system perceiving? When we treat behavior as communication rather than defiance, care becomes relational rather than reactive.

Predictability is one of the most powerful regulatory tools available in pediatric care. Narrating what will happen before touch, offering clear transitions, and slowing the pace of care restore a sense of control. Offering choices, even small ones like where to sit or which arm to use, returns autonomy to children whose bodies are often acted upon. These small acts of empowerment do impact on nervous system regulation in a positive way.

Equally important is recognizing how caregiver presence can help to regulate children's nervous systems. Separation during moments of distress can activate deep survival responses rooted in attachment. Allowing caregivers to remain close during procedures whenever possible supports regulation for both child and the parent. A calm caregiver acts as a co-regulator, lending their steady nervous system to the child in moments of fear.

Over time, trauma-informed interactions reshape behavioral patterns. A child who once escalated at every visit begins to enter the clinic with fewer defensive responses. The nervous system learns, slowly and through repetition, that safety is possible. Trust builds not through explanation alone, but through consistent experiences of predictability, gentleness, and respect.

It is also important to recognize that trauma-informed care does not eliminate medical necessity. Children still will require procedures, medications, and interventions that may be out of their control, uncomfortable or frightening. Trauma-informed care does not mean avoiding what must be done; it means doing what must be done in ways that minimize harm and maximize emotional safety. This approach not only reduces immediate distress but also protects long-term relationships with healthcare.

Providers often report that once a trauma-informed lens is adopted, frustration decreases and compassion increases. Behaviors that once felt personal or adversarial begin to make sense within a broader context of survival. This shift protects not only patients, but also clinicians, from the emotional fatigue that can accompany repeated behavioral crises.

Recognizing trauma responses in pediatric behavior fundamentally changes outcomes. Children experience care as safer. Families feel more understood. Providers move from control-based strategies to collaborative care. Each regulated interaction becomes a building block for future resilience.

It is also important to note that trauma does not stop at the patient's bedside. It travels through families, shaping siblings, caregivers, and relationships in quiet but powerful ways. When pediatric providers recognize and respond to these ripples with the same compassion and intention, healing becomes a shared process rather than an isolated outcome.

In pediatric settings, the focus naturally centers on the child with the most visible medical needs. The machines, medications, therapies, and crises demand attention. Yet trauma rarely impacts only one child. It ripples outward, shaping siblings, parents, relationships, and entire family systems in ways that are often unseen but deeply felt.

Siblings of medically complex children often live in a dual reality. On one hand, they may deeply love their brother or sister and want to help. On the other hand, they experience frequent disruptions, emotional neglect, fear, and confusion. Many learn early that their needs feel smaller than the medical demands surrounding them. Over time, this imbalance can quietly reshape various aspects such as identity, emotional expression, and their self-worth.

Secondary trauma develops not through direct medical procedures, but through proximity to chronic crisis. Siblings witness parental fear, overhear conversations about prognosis, endure extended separations during hospitalizations, and absorb the constant tension that fills the home. Their nervous systems also remain on alert, anticipating the next emergency even in moments of calm.

Some siblings step into a care-taker role, or can become hyper-responsible, trying to reduce burdens by behaving perfectly, helping excessively, or suppressing their own emotions. Others act out, expressing their distress through anger, regression, or withdrawal. These responses are also not attention-seeking; they are attempts to regain safety in an unpredictable world. Without recognition and support, sibling distress often goes unaddressed until it manifests in other areas of their lives, such as in school difficulties, anxiety, depression, or behavioral challenges months or even years later.

Family systems reorganize under medical trauma. Parents often function in chronic survival mode, balancing caregiving, employment, financial strain, and emotional exhaustion. Relationships strain under the weight of sustained stress. Emotional availability diminishes as logistics dominate daily life. Even strong families can feel disconnected under prolonged pressure.

Pediatric providers frequently encounter caregiver defensiveness, overwhelm, or rigidity. These behaviors are often misread as resistance to care or lack of engagement. In reality, they frequently reflect burnout, fear, and unresolved traumatic stress. When families feel judged rather than supported, trust erodes, and collaboration becomes increasingly difficult.

Trauma-informed pediatric care invites providers to widen their lens beyond the identified patient. When siblings are acknowledged, when caregivers are validated, when emotional reactions are normalized, families experience care as supportive rather than threatening. This broader perspective fosters alliance rather than opposition.

Even the smallest of actions can help communicate safety. Some of these actions are things like greeting siblings by name, explaining procedures at age-appropriate levels, encouraging parents to schedule individual time with each child, and normalizing mixed emotions. These moments restore dignity and visibility to family members who often feel overlooked. Over time, they rebuild connection where trauma has disrupted it.

Interdisciplinary collaboration plays a critical role in supporting families. When nurses, therapists, social workers, and physicians share insights and align around trauma-informed principles, families experience consistency rather than fragmentation. Unified care reduces confusion and strengthens trust. Supporting siblings and family systems is not an optional add-on to pediatric care. It is central to healing. When families feel emotionally supported, they engage more fully in medical care, follow through with treatment plans, and build lasting trust with providers.

Providers themselves are not immune to the ripple effects of trauma. Repeated exposure to suffering carries real emotional cost. Compassion fatigue, secondary traumatic stress, and burnout are common in pediatric care. Sustainable trauma-informed care requires systems that support clinician well-being alongside patient care. Teams that prioritize debriefing, reflection, peer support, and work-life balance foster resilience. When providers feel supported, they are more able to offer the calm, regulated presence that families desperately need.

Trauma in pediatric care lives in many areas such as behaviors, relationships, family systems, and the emotional lives of those who give and receive care. When providers begin to recognize behavior as a story of survival rather than defiance, and when they can widen their lens to include siblings and caregivers who absorb the quieter echoes of medical trauma, care becomes more effective. Trauma-informed practice does not require perfection or the absence of hardship; it requires presence, curiosity, and compassion in the face of suffering. When children feel safer in their bodies, families feel seen in their struggles, and providers feel supported in their roles, healing becomes a shared process rather than a solitary task. In this shared work, resilience grows, not as the absence of trauma, but as the collective capacity to move through it with connection, dignity, and hope.

Trauma-Informed Care

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Although this issue focuses on patients and families, we wanted to provide a working definition as a foundation for all of us. Trauma-informed care, in the opinion of the Pediatric e-Journal workgroup and all of its members, is a critical topic for providing quality care to all our patients and families. Because we believe this topic is so important, we are dedicating two issues to it. This first issue is geared towards patients and families, and the second issue, which will be distributed in May, is geared towards professionals and providers.

The following is a general overview of trauma-informed care, including definitions, listings of resources, and current literature. We invite you to share any initiatives/programs focused on integrating trauma-informed care in pediatric home health, palliative, or hospice care. Due date is March 30, 2026; please email Christy at Christy.Torkildson@gcu.edu

Definitions of Trauma

Trauma, as defined by the Substance Abuse and Mental Health Services Administration (SAMHSA, n.d.),results from events or circumstances that are experienced as physically or emotionally harmful or life-threatening and that have lasting adverse effects on functioning and well-being. Trauma can take many forms, including abuse (emotional, physical, sexual), neglect (emotional, physical), household challenges (substance misuse, mental illness, divorce or separations, incarceration, violence), bullying, exposure to violence, racism and discrimination, loss of a caregiver, and natural disasters. These experiences shape how children and families perceive safety, trust, and relationships. For children with serious illness or medical complexity, the effects of prior trauma may be compounded by ongoing medical stressors and repeated interactions with healthcare systems.

We often hear when a child with a complex medical condition is back in the hospital, that it is "normal" for this child and family; however, hospitalizations are rarely experienced as being routine or "normal." It is almost always a crisis for the child and family. Frequent hospitalizations and medical

interventions create chronic stress, along with ongoing loss of control and periods of uncertainty, affecting the child (patient), parents/guardians, siblings, friends, and other family members. The National Child Traumatic Stress Network defines pediatric medical traumatic stress as a set of psychological responses experienced by children and families in response to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences.

Medical traumatic stress in children may manifest across emotional, behavioral, and physiological domains, including heightened anxiety or fear, sleep disturbances, increased sensitivity to pain, avoidance of medical settings, difficulties with attention, emotional dysregulation, and social withdrawal (Ozbay et al., 2025). It is important to note that the impact of medical trauma is not static. Children's responses may change over time and are influenced by developmental stage and prior trauma exposure (Cuneo et al., 2023). Studies have also demonstrated that traumatic experiences can affect relationships, degrade trust in the health care team, and decrease adherence to care plans, including delaying medical care (Cuneo et al., 2023; Duffee et al., 2021).

These patterns of change over time and variation in response highlight that trauma is not inherent to an event itself but emerges from the individual's lived experience of that event. Trauma is therefore best understood as a subjective experience, shaped by how children and families perceive, interpret, and respond to stressors rather than by the events themselves. Two children may undergo the same medical procedure, yet one may experience it as traumatic while the other does not. Recognizing this subjectivity is central to trauma-informed care and guides clinicians to attend to each child's and family's unique perspective rather than making assumptions about what is or is not traumatic.

Finally, it is important to note that chronic stress and trauma are not isolated to children and families experiencing medical complexity, but may extend to helping professionals in pediatric palliative, hospice, and home health care, where repeated exposure to suffering and loss can lead to vicarious or secondary trauma.

Trauma-Informed Care

Recognizing that trauma may affect children, families, and the clinicians who care for them underscores the need for a trauma-informed approach that attends to safety, trust, and relationships across all levels of care.

Trauma-informed care (TIC) in pediatric palliative, hospice, and home-based care is essential for ensuring psychological safety, promoting resilience, and improving outcomes for both children with life-limiting illnesses and their families. By integrating core TIC principles—such as safety, trustworthiness, collaboration, empowerment, and cultural sensitivity—healthcare systems can address the layered trauma of terminal illness while fostering compassionate, ethical care. The American Academy of Pediatrics (AAP) has adopted the definition of trauma-informed care by Hopper and colleagues, as a "strengths-based framework that is grounded in an understanding of and responsiveness to the impact of trauma, and emphasizes the physical, psychological, and emotional safety for both providers and survivors, creating opportunities for survivors to build a

sense of control and empowerment." The AAP further describes trauma-informed care as "relational health care—the ability to form safe, stable and nurturing relationships" (AAP, 2025). The AAP has created multiple resources for both families and providers, which can be accessed at What is Trauma-Informed Care?

Trauma-informed care has been shown to increase resilience, improve relationships, and decrease medical trauma stress. For patients, TIC can reduce psychological harm, enhance trust and open communication, and support coping and emotional regulation. For families and caregivers, TIC helps build trust and a sense of partnership, encourages honest communication, and increases satisfaction with the healthcare team and system. As de Groot et al. (2023) note, "Trauma-informed palliative care acknowledges the emotional injuries families carry, and responds with compassion, collaboration, and dignity."

Resources

American Academy of Pediatrics: What is Trauma-Informed Care?

Center for Disease Control and Prevention also has resources that are available at About Adverse Childhood Experiences | Adverse Childhood Experiences (ACEs) | CDC

Courageous Parent's Network: Courageous Parents Network

Crisis Prevention Institute: Trauma-informed care resource guide: Trauma-Informed Care Resources Guide | Crisis Prevention Institute (CPI)

DC American Academy of Pediatrics: Trauma-informed care key messages and communications toolkit: communications_toolkit_8_14_23.pdf

Health Care Toolbox: The D-E-F Framework for Trauma-Informed Pediatric Care | Patient Centered Care and Trauma Informed Care for Pediatric Patients - HEALTHCARE TOOLBOX

Healthy Children.org: Trauma-Informed Care: Core Mission in Child Health Systems - HealthyChildren.org

National Center for Relational Health & Trauma-Informed Care (from the American Academy of Pediatrics): This site includes open access self-directed learning, on demand webinars, AAP reports and policy statements, resources to share with families, and much more: National Center for Relational Health and Trauma-Informed Care

Substance Abuse and Mental Health Services Administration: Trauma and Violence - What Is Trauma and Its Effects? | SAMHSA

The National Child Traumatic Stress Network: Trauma-Informed Pediatric Psychiatry | The National Child Traumatic Stress Network

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Building Resilience: Trauma-Informed Support for Children and Families in Disaster-Affected Communities

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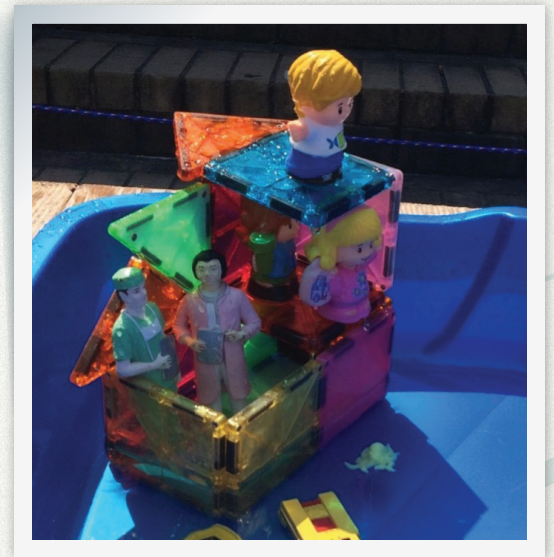
Children are uniquely vulnerable in the aftermath of both natural and man-made disasters, facing disruptions to safety, routine, attachment, and emotional stability. Such events often precipitate a wide range of adversities for children and families, including displacement, stigmatization, health inequities, loss of housing and possessions, educational disruptions, economic hardship, erosion of community support systems, and in severe cases, the injury or death of those they care about (National Commission on Children and Disasters, 2010). In the United States, ninety-four percent of children live in communities at risk of natural disasters—which is an estimated 73 million children in 2016 (Save the Children, 2012). It is estimated that there are 11 million children with special health care needs in the United States. Nearly 50% of children with disabilities depend on five or more healthcare services or specialized medical equipment, they face significantly higher risks for adverse outcomes in disaster situations (Hipper, et al., 2018).

As interdisciplinary response systems increasingly recognize the psychosocial needs of young survivors, Certified Child Life Specialists (CCLSs) offer a critical layer of support. Grounded in developmental theory, trauma-informed practice, and therapeutic play, child life specialists help children make sense of frightening events, regain a sense of control, and access adaptive coping strategies. This article examines the essential role of CCLSs in disaster preparedness, response, and recovery, highlighting how their specialized skills can mitigate trauma, strengthen family resilience, and promote healing in the most chaotic and uncertain circumstances. These strategies and resources can also be utilized by parents, teachers and the general public.



A water play scene created by a 7-year-old girl who with her family was rescued from her roof by the fire department when her home quickly flooded.

According the Child Life Disaster Relief (CLDR) website (2025), “Evidenced-based interventions for children, especially in the immediate aftermath of a disaster, point

to the specific value of child-centered play opportunities implemented by individuals trained in children's trauma and grief responses. Also, there is a huge need for professionals who can mitigate stress and trauma for children and maximize positive coping through age-appropriate support and interventions in the midst of the chaos of a disaster." Child Life Disaster Relief is a non-profit organization that was founded in 2016 "to empower and support children and families in crises by providing trauma-informed direct services, community outreach, training, and education" (Child Life Disaster Relief, 2025).

Child Life Disaster Relief volunteers have deployed to many disasters in the United States since its 2016 inception, including hurricanes, tornadoes, wildfires, earthquakes in Puerto Rico, COVID-19, flooding, and typhoons. This writer had the sincere honor to deploy to Hurricane Florence in 2018 in North Carolina in coordination as a child life specialist with Children's Disaster Services and The American Red Cross, and to the Puerto Rico Earthquakes in January 2020 as a CLDR Responder with B&R Emergency Training and Response Corp.

The 2023 Child Life Disaster Relief Trauma Mitigation Model offers evidenced-based strategies for practical application. This includes co-regulation of first calming one's own emotions and modeling coping strategies. Connection refers to getting down on the child's level and using non-verbal body language to reassure them that you are facing this challenge together. Cognition can occur once the child is in a regulated state to build emotional safety and disclose simple, honest language about the disaster. Control creates predictability and routine, and offers opportunities for autonomy and free play.

According to the Trauma and Grief Center at the Meadows Institute (2025), there are "Six S's" designed to support children ages six and older after a disaster. They are:

1. Safety & security
2. Simple & straightforward language
3. Supervision
4. Structure
5. Social support
6. Self-care

The primary focus when children and families first come to a disaster shelter is to reinforce their current safety and to offer space for them to process what they have been through in evacuating from the disaster. Many people become stranded and rely on first responder assistance to evacuate to safety. Children and their families bear witness to tragedy including loss of belongings, property, pets, and human life. There are often more questions than answers about the safety of loved ones and when or if they can return to their home. This time can be a sensory overload with many loud noises such as sirens and screaming and strange people in an unfamiliar environment. Providers and parents must understand that this involves a form of grief and guide children through it by creating a calm, safe space, validating their emotions, and modeling healthy coping strategies.

Parents and adults should use honest, direct language and ask open-ended questions to allow for further exploration of developmental understanding and concerns. Additionally, limiting children's

access to media coverage (online, on television, and in print) of the disaster can prevent re-traumatization (Disaster and Community Crisis Center, 2011). This is another time caregivers can spot check worries and feelings with children and answer new questions that they may have even if the response to the question is "I don't know" or "that worries me too." Structure can provide children with normalcy and predictability during a time of disaster. For example, a bedtime story, even one played on YouTube if the physical book is not present, can offer comfort and routine in a shelter environment.

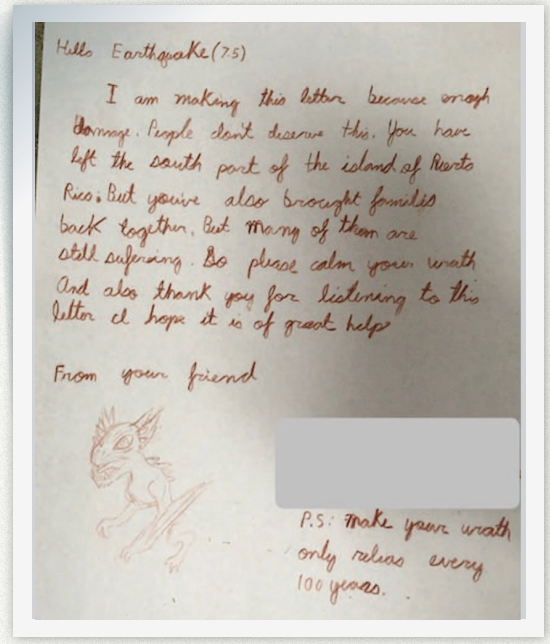
Social support also promotes resilience, which takes many forms including the Red Cross & First Responders, neighbors, teachers, family, friends, social media, Go Fund Me, and Good Samaritans. This writer recalls two Good Samaritans who drove through the night from Mississippi to deliver a U-Haul packed with donations to a middle school shelter during Hurricane Florence in North Carolina. The morale lift it provided—to both the survivors who had lost everything and the Red Cross volunteers—remains unforgettable, especially the joy it brought two school-aged brothers who received new shoes after their home flooded. After a disaster, reconnecting children to sources of social support (e.g., parents, teachers, peers, extended family, coaches, or mental health professionals) improves their mental health and well-being (Bakic & Ajdukovic, 2021; Lai et al., 2018).

The final "S" the Trauma Center and Grief Institute discusses is self-care. "Children whose parents were highly distressed following natural disasters appeared to have a greater number of disaster-related problems than children whose parents were not so distressed (Gil-Rivas et al., 2007). This follows the oxygen-mask principle used on airplanes, which reminds us that one must first care for oneself to effectively help others, which is easier said than done. In order to best support children impacted by disaster, parents must be educated, empowered, and assisted to promote their positive coping both in the immediate and long-term aftermath of a disaster.

Mental health support is important for responders as well. Scholars have employed the term *secondary traumatic stress* to refer to the emergence of PTSD-like symptoms among professionals who engage with trauma survivors or among individuals who provide support to traumatized relatives or acquaintances. Despite its omission from contemporary diagnostic manuals, evidence from clinical practice suggests that indirect exposure to traumatic events can give rise to symptoms similar to those observed in PTSD. (Stamm, 1995).

A final consideration to promote resilience in children affected by disaster is the power of play. After the 1995 Kobe, Japan, Earthquake, increasing reports of PTSD underscored the need to prioritize children's mental health services. Pediatric doctors in the region subsequently endorsed children's play as a therapeutic strategy designed to relieve stress and mitigate the risk of PTSD by promoting a return to everyday routines (Kinoshita & Woolley, 2015). Additionally, adventure playgrounds were built to give children a space to play through the disaster of the earthquake and tsunami they experienced with the supervision of counselors (Okuyama, 1996). It is imperative that children, teens, and adults have opportunities for free play to allow for release of nervous energy, along with art supplies to encourage self-expression, bubbles to promote deep breathing, and costumes and vehicles of first responders to process their experiences. Additionally, play offers social support and bonding with others who have shared experiences.

This certified child life specialist co-facilitated a therapeutic play space during her weeklong Hurricane Florence deployment at a middle school for 35 children along with two other certified child life specialists and two other volunteers based on the Children's Disaster Services model. Opportunities for water play at a picnic table with Magna tiles and figurines became a powerful, sacred play space in which children processed their evacuation. One seven-year-old child silently built her house with herself and other figurines on the roof with their cars underwater. She played out firefighters rescuing them on a toy boat and then knocked down the house once they were safe. Another 10-year-old child openly shared how she had to swim out of her home in waist deep water while her mother escaped with her two-year old brother. She stated she was "really sad that my baby book was ruined along with my keyboard my grandpa gave me. My easy-bake oven and roller blades got messed up and I wasn't able to grab any of my toys." Our team validated her feelings and offered emotional support and further outlets throughout the week while other children voiced their similar experiences. Activities took place inside the cafeteria, outside on picnic tables and races and games on the track and field to allow for a variety of outlets for nervous energy through play, art, bibliotherapy books, and physical activity. Local police officers, firefighters and National Guard also visited and the children were able to ask them questions. Developmentally appropriate resources were given to the parents to educate them on how to speak with their children about disaster. Other assistance included bibliotherapy books to read together and the need to follow-up with local counseling if prolonged coping difficulties persisted. While the team offered support and technical advice, the lessons from the children and families taught the team so very much as well.


Hello Earthquake (7.5)

I am making this letter because enough damage. People don't deserve this. You have left the south part of the island of Puerto Rico. But you've also brought families back together. But many of them are still suffering. So please calm your wrath. And also thank you for listening to this letter. I hope it is of great help.

From your friend

P.S.: make your wrath only release every 100 years.

A letter written by a 7th grader to the earthquake.

In Puerto Rico, the Child Life Disaster Relief team of four child life specialists worked with classrooms and teachers as they returned to school following earthquakes. They invited students from kindergarten to eighth grade to write a letter to the disaster and draw or paint their experience to allow for self-expression. Teachers also shared how they were processing their own anxiety and grief while trying to be supportive to their students. The team validated feelings and educated them all on deep breathing and guided meditation techniques. Safety plans and evacuation drills were also reinforced both at school and for their homes.

Based on the concept of the Children's Disaster Service's Kit of Comfort and creating makeshift play spaces wherever the need arises, this child life specialist was awarded a grant from the Northeast Florida Regional Counsel for Emergency Preparedness Services for 100 backpacks filled with coping items on behalf of Child Life Disaster Relief. She and a fellow child life specialist created them for four categories to support infants and toddlers, school age, teenagers, and those with developmental differences. Each backpack was filled with the previously-mentioned supplies and included

developmentally appropriate coping tools to help children process and manage their emotions. Educational cards were included to assist caregivers with developmentally appropriate language to explain disasters and promote positive coping. These can be easily replicated and adapted to support children in any setting.

Mr. Fred Rogers said, ***"When I was a boy and I would see scary things in the news, my mother would say to me, 'Look for the helpers. You will always find people who are helping.' To this day, especially in times of 'disaster,' I remember my mother's words, and I am always comforted by realizing that there are still so many helpers—so many caring people in this world."*** If you are still reading this article, you are most likely one of those helpers and on behalf of all you will assist in your lifetime, thank you for making a difference!

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Children's Grief Awareness Day: A Special Way to Educate, Equip, and Honor Those Who Experience Grief

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"What is Children's Grief Awareness Day?

Created in 2008 by the Highmark Caring Place, A Center for Grieving Children, Adolescents and Their Families, and since recognized by organizations around the world, Children's Grief Awareness Day is observed every year on the third Thursday in November (the Thursday before the U.S. holiday of Thanksgiving). This time of year, is a particularly appropriate time to support grieving children because the holiday season is often an especially difficult time after a death." 1

To join this special day of Children's Grief Awareness, it was a humble privilege to collaborate through the lens of Nursing and Spiritual Care, as a Bereavement Care Coordinator and Palliative Care Champion, I felt called to bring this important event to our hospital. With the wonderful support of Sonia Carter, Director of Patient Experience at Manning Family Children's, who was invaluable in assisting to orchestrate this beautiful event. Together with our Pastoral Care Team, Trauma and Grief Center Team, Child Life Specialist, Language Access Team and our Palliative Care Team, we hosted our first Annual Children's Grief Awareness Day at Manning Family Children's on Thursday November 20, 2025. This was an opportunity to show our support to all who experience grief, especially our children on this day, by wearing blue and providing a Wall of Hope on which messages could be written to share our support. In addition to these messages, our Child Life Specialist offered an opportunity to make a wall of butterflies with colorful tissue paper. This was a warm invitation to participate in a non-threatening manner. The colorful display of butterflies, blue balloons, a large

butterfly kite, and warm messages of support and love was a great way to show support and honor those we grieve.

It was also an opportunity to share many resources and activities to promote healing and growth as we grieve and the way our grief is impacted at developmental stages and individual experiences. Many great resources are provided through the website for Children's Grief Awareness Day. 2 "Helping children and teens say goodbye" is a booklet offered through our Child Life department. "Children and teens need the opportunity to say goodbye to a loved one who is dying. During this difficult time there are ways to help children and family members "say goodbye."3

Another valuable resource offered and printed in both English and Spanish was a flyer, from the Trauma & Grief Center, "Five Signs a Grieving Child or Adolescent May Need Extra Help"4

Every child expresses their grief differently. However, there are times which youth feel especially "stuck" in their grief and need additional support."4

The Five Signs to Look For:

- Significant Developmental Regressions
- Extreme Separation Distress
- Excessive Preoccupation with the Circumstances of the Death
- Avoidance and Numbing
- Risk-Taking Behavior

"Again, every child grieves differently, and there is no set timeline for grief. But if any of these behaviors

(1) Are present after six months post-death; (2) impact daily functioning; and/or (3) include expressions of self-harm or suicidal thoughts, we would encourage caregivers to have the child evaluated by a mental health professional who is well-versed in the assessment and treatment of childhood grief."4

For More Information Contact:

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"Manning Family Children's offers our community The Trauma and Grief (TAG) Center

The TAG Center provides evidence-based assessment and treatment for children and adolescents, ages 0 to 21, who have experienced any form of trauma and/or the death of a loved one. Using state-of-the-art screening tools, the TAG Center ensures that youth receive the most appropriate and effective treatments."4

Grief is part of our life story. For children, this will be impacted by their developmental stage. This is an ongoing process. Contemplating what it means to no longer have someone in your life who has been interwoven into all aspects of our lives. This can be a process with highs and lows, a range of emotions. Sometime grief can feel like waves, some gentle while others are overwhelming and not always anticipated. All these emotions are an important part of processing this significant loss. Be gentle with yourself and learn to recognize the need to support one another, especially our children.

In his book, *A Grief Observed*, C.S. Lewis, describes grief in this way: "No one ever told me that grief felt so much like fear. I am not afraid. The same fluttering in the stomach, the same restlessness, the yawning." His ability to describe the sensations associated with emotions of grief paints a vivid picture of what he experienced, though grief is unique for all of us. He shares with the reader another important aspect that grief is ever changing. "In grief nothing 'stays put.' One keeps on emerging from a phase, but it always recurs. Round and round. Everything repeats. Am I going in circles. Or dare I hope I am on a spiral? But if a spiral, am I going up or down it?"5

In all these mixed emotions associated with grief, it is most important to reach out to those in need. We want to especially be aware of the needs of our children and teens who grieve.

What is Children's Grief Awareness Day?

A day to keep in mind that children may have a difficult time after someone dies. Remember to show your care and support.

When is it?

The third Thursday of November every year (the Thursday before Thanksgiving). Holidays can be difficult for one who is grieving; giving them extra love and support helps them.

Why Observe Children's Grief Awareness Day?

Children who grieve do not just "get over it." Extra support and understanding are important and for a longer time than most people assume.

"Join children, teens and adults across the nation and the world in helping grieving kids know they're not alone!"6

It is our hope to continue to support Children's Grief Awareness Day on the third Thursday of November annually and to present a strong presence of love and support to those in need, offering resources to Honor, Equip, and Educate!

References

1. https://www.highmarkcaringplace.com/cp2/index.shtml/
2. https://www.childrensgriefawarenessday.org/cgad2/index.s
3. https://manningchildrens.org/
4. https://www.manningchildrens.org/services/behavioral-health/trauma-and-grief-center/
5. Lewis, CS, A Grief Observed; Harper One Publishing, 2009.
6. https://www.childgriefday.com/

Readers' Corner

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Leyenaar JAK, Arakelyan M, et. al. Hospitalizations by Children with Medical Complexity from 2009 to 2022. *Pediatrics* 2025;156(2). e2025071774

Summary: This article reviews the increased risk of hospitalizations and in-hospital mortality among children with medical complexity (CMC).

Who will benefit from this information? While this is particularly helpful for hospital providers who care for CMC, it also supports health care providers, programs, and policies supporting CMC in community based settings.

What is the burden of hospitalization by CMC?

- There are more CMC secondary to an increased survival of extremely low birthweight babies and medically complex children.
- CMC have a higher risk of hospitalization (25%) and in-hospital mortality (40%)
- Most CMC are initially in general hospitals and frequently need transfer to children's hospitals which may be far from home
- From 2009 to 2022 there has been a slight decrease in hospitalization especially in children's hospitals, and an increase % of hospital days and costs accounted for by CMC
- CMC admissions accounted for >90% of pediatric hospital deaths

Where do we go from here?

These data can be the basis to justify and develop programs and policies to improve the care and support of CMC in both community based settings and children's hospitals.

Items of Interest!

Please help us keep the items of interest up to date. Share your news, upcoming conferences or webinars. Are there particular podcasts that may be of interest to our readers? Send any items of interest to Christy at Christy.Torkildson@gcu.edu**. Thank you.**

1. **AAHPM & HPNA Annual Assembly 2026 will be in San Diego, California, March 4-7, 2026.** Click HERE for more information. There are several pediatric sessions, including a pre-con, "Beyond the Script: Educating for Empathy and Impact in Serious Illness Communication," on March 4th, 1-5 PM. There are also several networking sessions for pediatric interest groups!
2. **33rd Become an EPEC-Pediatrics Trainer Conference Education in Palliative and End-of-life Care (EPEC) – Pediatrics;** Hotel Andaluz, Albuquerque, New Mexico, March 24-26, 2026. Plus Optional: EPEC-Pediatrics Professional Development Workshop (PDW), March 27, 2026. Additional Information about EPEC Pediatrics
3. **Pediatric Palliative Care Webinar Series for 2026** has started with our greatest number of participants. Do not miss out! Calendar and more information, including how to register, can be found at https://www.ppcwebinars.org/
4. **The Alliance for Care at Home Finance and Technology Summit** will be on July 12-14, 2026, in Boston. Registration is now open
5. **Alliance for Care at Home Advocacy Week** is September 13-16 in Washington DC; please save the date!
6. **The Alliance for Care at Home Annual Meeting and Exposition** will be held October 27-30, 2026, in Washington DC – Registration is open!
7. **Please save the date!** The Alliance for Care at Home Annual Meeting & Exposition for 2027 will be held October 19-22 in Seattle, WA.
8. **The National Coalition for Hospice and Palliative Care** has named the leaders to the next revision of the Clinical Practice Guidelines for Quality Palliative Care, 5th edition. Congratulations to all! More information can be found HERE
9. ELNEC **has several upcoming courses**; if you are faculty, you can get free access to the curriculum for the program/courses you teach. Click HERE for more information.
10. **A wonderful resource that may be helpful** is "Not if, but When), a website that "encourages and supports sharing good books and stories about death and loss with children and teens throughout their lives." Website: https://www.notifbutwhen.org/

11. **Courageous Parents Network has a whole new website!** There is a wealth of resources for family members and providers. Click HERE for more information.
12. **Academy Health: Enhancing Systems of Care for Children with Medical Complexity Newsletter** is a collaborative project with the University of San Francisco, Family Voices, Boston Children's Hospital, Patient Insight Institute, Patient Advocate Foundation. More information can be found HERE.
13. **The Lucille Packard Foundation for Children's Health publishes the Children and Youth with Special Health Care Needs Network Newsletter** – includes news, policy updates, resources, events, and advocacy opportunities from across the nation. You can subscribe to the newsletter by clicking HERE.

Are there any Items of Interest you would like to share? Are there resources that you love? Please email Christy at Christy.Torkildson@gcu.edu

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for Care at Home

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