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COMMUNITY BRIDGE OF SUPPORT

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Pediatric e-Journal Pediatric Palliative and Hospice Care

Issue #79 | June 2025

Issue Topic: Community Bridge of Support Part One

Welcome to the 79th issue of our Pediatric e-Journal. Our focus in this issue is on ways in which individuals, programs, and communities are or can work together in support of pediatric hospice and palliative care. Working together can take many forms, many of which depend on the individuals involved and the communities in which their efforts are located.

These are very large topics and they have brought to us a superabundance of important articles. In fact, we received so many articles in which contributors were eager to describe what they were doing to support children, adolescents, and family members that we have found it necessary to divide this subject into two parts. Part One will now be Issue #79 which you are currently reading. Part Two will follow in three months as Issue #80. And our plans for an issue on adolescents and young adults will now become Issue #81.

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), formerly the National Hospice and Palliative Care Organization (NHPCO). 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 on the Alliance website. **Note:** The Alliance website is newly launched, and some pages are in progress. If you have issues accessing a previous edition, please email communications@allianceforcareathome.org for support.

Comments about the activities of the e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are open to suggestions for or contributions to the two issues that will follow in 2025. Our first issue in 2026 (Issue #82) will address trauma and trauma-informed care. If you have any thoughts about these topics or other subjects for future issues in 2026 and/or potential contributors (including yourself), 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.

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Susan Finke RN, BSN, CHPN

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I Want to Go Home: The Role of Palliative Care Transport p. 13

Samuel M. Kaplan, MD, MPH, and Jenni Linebarger, MD, MPH, FAAP, FAAHPM

"Palliative care transport allows critically and terminally ill children, who are receiving life-sustaining treatments, the opportunity to return home for end-of-life care. This intervention offers an alternative to hospital death, even for patients too ill to travel by private vehicle…This article reviews the benefits, barriers to implementation, and the policy framework developed at Children's Mercy Kansas City. We also share our experience with the challenges and successes of our palliative care transport program."

Family Certified Nursing Assistant/Home Health Aide Program p. 18

Bill Sczepanski, Vice President, Government Relations

"The worsening nursing shortage is having a devastating impact on private duty nursing (PDN) services, particularly for pediatric patients and their families." In that context, this article describes programs in several states that "have allowed parents and family members to become state-certified caregivers through equivalent programs to certified nursing assistants (CNAs)." According to available data, "this model has led to hospitalization rates 90% lower than the national average, underscoring the critical role of stable, trained caregivers in maintaining health at home. The reasoning is simple: children authorized for home health nursing are fragile but stable, and maintaining their stability requires consistent, reliable care from trained caregivers. Family members—who never miss a shift and understand their child's needs better than anyone—play a crucial role in this continuity of care."

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Matthew Misner, DO, MS, MAPS, and Jamie Jacobs, MSW, LSW

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Kristin James and Betsy Hawley

This article describes a free resource, When a Child Dies: Planning Acts of Love & Legacy, that offers guidance, inspiration, and decision-making pathways to help families with the funeral process. The booklet is part of an innovative partnership with the Funeral Service Foundation (FSF), the National Funeral Directors Association (NFDA), Pediatric Palliative Care Coalitions (PPCC), and bereaved families to develop educational guidelines, identify resources, and build strategies to improve the experience. Contributors to this booklet included parents, healthcare providers, grief specialists, and funeral professionals. The booklet identifies seven important points in the funeral planning process to emphasize working together with families as they plan end-of-life rituals and prepare to say goodbye to their children: Transfer of Care; Preparing the Body; Planning the Service & Final Resting Place; Memory Making & Legacy Building; Sibling & Youth; Grief Support; and Collaboration & Community. (multiple photos within the text)

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Lisa C. Lindley, PhD, RN, FPCN, FAAN

“Measles is a highly contagious viral infection that primarily affects children and can lead to severe health complications, even death. Despite the availability of a highly effective vaccine, measles has surged and continues to claim the lives of children worldwide…[and] especially in areas with low vaccination rates such as Texas. In this article, the author “explores how measles leads to fatal outcomes in children, and how hospice and palliative care can play a crucial role in supporting both the child and their family during such difficult times.” The author’s conclusion is that, “Parents and communities need to be educated about the importance of vaccination to prevent measles outbreaks. But for those who do face the consequences of the disease, knowing that hospice and palliative care services are available can provide some comfort during an incredibly painful experience.”

Finding Hope & Support in Unconventional Community Therapies

Kaycee Jakubowski,
Leo’s Mom & Parent Advocate for The HAP Foundation
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My partner Jeremiah and I possessed the goal of expanding our family for some time. We never imagined how our dream of bringing a happy and healthy child into our family would change our and our other children’s lives and futures forever. Our son Leo was born in 2019 appearing normal outside of slight jaundice and some failed cardiac tests that resulted in a month-long NICU admission. Leo was discharged home healthy and without a diagnosis. We thought everything was fine until he was a few months old, when our happy son began regressing and failing to meet developmental milestones. Concerned, we took him to the pediatrician who referred us to neurology, as well as early development specialists, for assessment. Leo was diagnosed with developmental delays. It was also found that Leo was experiencing infantile spasms and seizures. This information was devastating, and we were desperate for answers, yet continued to hear that all we needed was to increase tummy time to improve his functioning. This dismissal of our concerns was something I sadly learned is common. This dismissal also resulted in a delayed diagnosis, which ultimately took years away from my child. I will never recover from our lost time, as a piece of my heart died in the knowledge we could have had over ten more years with Leo with a timelier diagnosis.

After months of advocating and fighting to obtain answers/solutions, Leo was diagnosed with Menkes Disease at 11-months-old. Menkes Disease is a rare, X-linked recessive disorder that affects copper metabolism and leads to neurodegeneration and ultimately death. It is a terminal illness for which there is no cure. Subsequently, after diagnosis we started our only available intervention, symptomatic treatment. Jeremiah and I were taught how to use a suction machine, feeding pump, g-tube, and to administer medications and basically keep Leo alive in a home environment at that time. This was a process that required an extended hospitalization until these skills were learned. Long hospitalizations are something parents of children with medical complexities know create significant emotional distress and implications on all other domains of life, including parenting siblings, family time, finances, and employment.

Leo was admitted to hospice before his first birthday after the hospital discharge. We were informed he had less than six months to live should the disease take its natural course. Despite this prognostication, Leo spent over three years involved in home hospice. Leo and our family had a wonderful and supportive, pediatric-based, hospice team behind him and our family. Enrolling in hospice right away was one of the best decisions we could have made for Leo. We were blessed with the most amazing hospice nurses, social worker, and child life specialist that we love to this day. Whenever I had a question or needed help with something they were just a call or a visit away: They were always willing to help. They were also incredibly beneficial in helping bridge-the-gap that existed between home life and hospital specialists.

Jeremiah and I found that many providers were quick to dismiss Leo's abilities and quality of life when we would describe his home life and overall functioning during hospital/specialist appointments. This was frustrating as they only saw Leo while he was in the hospital with suspected sepsis or pneumonia. We felt they did not understand the complete picture of the child in front of them and only saw his diagnosis or current presentation. I say this not to degrade hospital staff, rather to highlight how our hospice nurses were always willing to call or send a quick photo of Leo winning an award at his horse show or floating in a pool with sunglasses on to try to explain he was not in a state of distress or decline most of his life. Our hospice team was attempting to illustrate how Leo was living life to the fullest and continuing to advance and grow despite his illnesses, setbacks, and disease progression. Our hospice team also helped by intervening, more than once, to ensure we were receiving the care we expected/desired, that our wishes were heard and followed, and that Leo's best interests were in mind for all treatment decisions.

In addition to our amazing hospice team, I want to highlight other community providers that promoted Leo's quality of life. Several of the therapies that were supposed to benefit Leo did not seem to help and were extremely difficult for him. We knew that if Leo was ever going to get stronger and outlive his prognosis, he needed good therapies and intervention. Jeremiah and I were forced to search for unconventional therapies to support Leo. In my panic, I remembered growing up with cousins diagnosed with Down Syndrome and the joy and skills that horseback riding brought them. Based on this, I and Leo's father began the battle to get him on a horse. A large issue for children affected by Menkes Disease is osteopenia, resulting in frequent fractures and brittle bones, making my argument weak.

Through pure persistence, Leo was participating in Hippotherapy, also known as equine therapy, within a few months. The joy these horses brought him was unmatched. Our equine therapy program had amazing therapists that worked with Leo and supported him to breathe and feel his best; they just seemed to understand him. He was gaining strength, his respiratory functioning increased, and he was improving emotionally every visit. Leo always loved getting out of the house, but he really enjoyed riding and petting the horses. Leo would trick-or-treat with the horses every Halloween, take part in their yearly horse show, and he developed a community that loved him and wanted the best for his future. It was amazing to be able to invite family to Leo's horse show or take part in his yearly fundraisers when there were not many ways to support him otherwise. Having an event to look forward to and watch him take part in with other children was an experience we all enjoyed and one that brought a lot of excitement to all of our lives.

We also found the most amazing and supportive community in chiropractic care. Weekly adjustments were something we all looked forward to, as Leo would get adjusted, my daughter would play with other children, and I had a community of care advocates that always supported our family and genuinely tried to make our lives easier. Chiropractic care brought better breathing, mobility, emotional wellbeing, and most importantly comfort to Leo. Leo also enjoyed aquatic therapy. He gained so much strength from swimming. It was the only time he was free from gravity and able to move in ways we never thought possible. We would go to our local health club outside of lessons and use the warm water therapy pool, with his suction bag and oxygen tank sitting on the edge, to float in his flotation device, swim, and move freely. Through these experiences, I found that most of the time places are willing to accommodate and help if you ask. I learned to not feel shame or fear in taking my medically complex child out in society. The machines and extra accessories may be loud and intrusive at times, but they are essential and should be treated as such.

I'm writing this article to dispel the myths around hospice care. I also want to highlight therapies that are not commonly recommended or even talked about within special needs communities or by traditional doctors. I'm writing this to let others know how hospice care and these therapies provided us with wonderful friends, unconditional support, incredible therapists, and amazing benefits to Leo's life. Without finding these programs, we would have never made the lifelong friends that have supported us through the rough times, provided a shoulder to cry on or vent to after a stressful appointment, or get us through long hospitalizations. It was also refreshing to find other parents that had experienced the same struggles as our family and understood the day-to-day struggle of trying to raise a child with a complex medical disorder. More importantly, it brought hope to our family that we would have more time with Leo and improved our belief we could keep him comfortable as he battled his disease.

Leo may have been non-verbal, but he was active in his community and enjoyed every day he spent on this earth. Leo spent his weeks riding horses, swimming, participating in field trips with his preschool class, went to every sports event that he could, and even served as the honorary captain for the 2023 11U Algonquin Argonauts Football Team. Ultimately, Leo may have had a terminal disease but he was thriving and we were able to build a community around him filled with love and support. I urge all of you parents to find and create that community for yourself. Inclusion is what you make it to be, and I believe all children, medically-complex or not, deserve to enjoy and take part in their communities and be involved.

Leo ended up passing away last January. My hope and reason for my involvement in the HAP Foundation, and even writing this article, is for other children just like Leo to find the same strength, joy, and support in their communities that Leo found. I want to give the information and support that promotes more focus on quality and comfort in life. My goals for the future are focused on spreading information about the importance of a great home-based hospice and palliative care team for children and families affected by medical complexities. I hope to educate providers and parents on the power of therapies not covered by insurance, including hippotherapy, aquatic therapy, chiropractic treatment, and more. I hope to advocate at local, state, and national levels to promote the importance of these community-based programs on the quality-of-life for patients and their families who experience the heartbreak of their child requiring pediatric palliative or hospice care.

Figure 1: Leo loves the feeling of floating on the water

Hope is possible and lives all around us. While searching for answers and support as a parent of a child with complex medical needs and/or a terminal illness, you could feel emotionally drained, scared, lost, or frustrated. I joined the HAP Foundation Pediatric Parent Advisory Committee (with five other mothers of children affected by childhood cancer or medical complexities) as a way to keep Leo's legacy alive and support others with shared experiences. We are starting a support group for parents of medically complex children or children affected by childhood cancer to bring hope, joy, and support to Illinois families. We have assisted in the creation of a robust resource guide. We are helping HAP advocate for legislation that supports medically complex children in our state. I just hope Leo is watching with pride and approval as we attempt to bring others the joy he brought us.

Figure 2: Leo and his mother;

For information about the Hap Foundation (Hospice and Palliative Care Foundation Research & Education), contact www.thehapfoundation.org or call 312-741-1283.

Creating Brave Spaces: End-Of-Life Doula & Community Based Support

Toula Saratsis,
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Community Death Care Educator
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Guest Speaker @ UM School of Social Work Death, Loss & Grief interdisciplinary class for students from social work, nursing, public health, pharmacy and genetic counseling.

> *Communities find their health and resilience by discovering the wisdom and wealth already present in their people, traditions and environment.*
>
> **Margaret J. Wheatley**

The moment my 3-day old baby almost took her last breath was when I became a doula. An unexplainable intuition guided my thoughts, actions, and requests. Angelica needed me to advocate for her spiritual needs and comfort. No one directly informed me that she may die. That inner wisdom led me to reframe the experience to companion my child and validate her voice and wishes. This knowing repeated throughout nearly seven years of nurturing, medical crises, and illnesses until nursing her through the dying process. We were surrounded by our community of diverse people that shared the responsibility of supporting our family as we focused on her well-being. She was raised not to fear death as it was a daily possibility given the medically fragile status of the genetic disease that had its own story to tell.

End-of-Life Doulas are non-medical practitioners with varying skills, talents, and natural abilities called the knowing. They provide a safe container for heavy emotions and guide people through difficult situations, helping them control their own narrative. Our culture hesitates to embrace the certainty of death, overlooking the natural process. Community death care traces back to before the medicalization of helping others through final transitions. Doulas modernize this ancient practice, bridging the needs of those they serve with mainstream systems. They are non-judgmental, connect existing networks, and creatively pursue ways to integrate challenges and opportunities for people's voice to be heard through the lens of cultural competency.

Stewardship of people's voices, especially children, requires doulas to forge partnerships with existing circles of care. Dialogue leads the way to seek understanding from the child and all those involved in their support. Education, sharing resources, and most importantly being present highlights the skills that can be self-taught through experience and/or acquired through training. The pediatric doula is an emerging, grass roots specialty in the doula training and professional worlds. At this time, many serving families work in isolation, although this is changing. Community death care is not an approach to implement, but rather it is a way of being. We naturally gravitate towards helping each other in practice, service, and companionship.

The role of who helps depends on availability of people and services. Resourcefulness distinguishes the doula way. Honoring professional boundaries and limitations differentiates between the knowing and the doing. “I have not worked with children before,” read the message from a doula reaching out for support while guiding the preparations for the home funeral of a young child in hospice. “You already know what to do. Let the child, family, and community lead you,” was my reply. I sent resources and shared practical information from experience.

The doula held the space for them, researched the logistics of their requests, and collaborated with the hospice team. The home funeral had been the most beautiful the doula supported. The story posted about it humbled all of us in its description of how the child and family bonded on the death bed, creating memories and saying goodbye how it felt best for them. Community death care eliminates the “they” and “them.” It is about the “us” and “ours.” We do not work in opposition or competition.

Tending to the sick and the dying carries an ethical responsibility. The idea that community-based support promotes a collective goal to provide presence without being intrusive inherently creates brave spaces. It is us, the families, community members, clinicians, end-of-life practitioners, and after-death care providers that walk alongside each other. The openness of turning towards our suffering as we bear witness to the unfolding of sad and heavy experiences keeps us grounded.

Pediatric palliative care services plan for successful and meaningful outcomes in the path of many unknowns within the framework of the medical system. The structure and nature of it invites a natural partnership with community based support. Building trust is a common thread in our work. The intimacy of serious illness, unknown prognoses, and death mirrors beliefs and practices that people may hesitate to share. Similarly, the shock of knowing a child could die or has died tends to keep people stuck and unable to proceed with difficult decisions. The doula, an outside consultant, represents a different relationship. The constraints of timelines, protocols, and limited resources which are standard barriers, generally do not support an organic unfolding of events. This is where the knowing and intuition provides helpful insight.

Figure 3: Toula Saratsis Leading Education Initiative

Who can be a doula? What qualifies doulas to do end-of-life work? Are they a liability to mainstream systems? How can the community be involved? All valid questions and often asked. The long and the short of it is that anyone can be a doula. Whoever is able or willing to step up and help the child and their family. Essentially, it is the person or people they trust to act as guides. That is where community death care education can influence cultural change for a shared vision.

Perhaps the family has a spiritual advisor, friend, or neighbor that understands and will be that bridge for an often overwhelming reality to navigate in the midst of life’s responsibilities. This is not the failure of the system. It is human nature. Our family's spiritual needs were in the hands of our Greek Orthodox priest that often visited us in the hospital and attended family meetings. There were times that my daughter's Aunt stepped in as our doula in the hospital, at home, and in the end as we held Angelica together on the death bed.

Figure 4: In loving memory of Angelica E. Stageman

End-of-life doulas represent a movement of palliative and death care that presents a remarkable counterpart to the people that work tirelessly to change a complicated system. Professional fears of working with the community is a step we can take together in this conversation. From my consultation work with programs and systems, there may be pediatric doulas on staff working alongside medical professionals in the future. The interest is there and the dialogue open.

Relationships are not perfect but worth the investment of time and energy to examine existing connections. This calling that took hold of my spirit caring for Angelica has given me the privilege to serve children and their families. Also, sharing in education on various platforms and initiatives. In this advocacy, I, too, have not always been fully accepted.

There are doulas (some with clinical backgrounds) and other community members that talk about the frustration of not being welcome into clinical space to help support. Not an obstacle but a possibility. Curiosity is the mantra of innovation. Building sustainable practices for a broader outreach to equitably serve all children is a process. Community bonds us by visible and unseen forces. In collaboration, preparing my child for her death was the greatest gift we could give her to live well. Our children deserve a cohesive, safe and authentic path and passage. With love in community.

Guidance for finding an End-of-Life Doula

Anyone you trust can help you, your child and family. Doulas can be trained or serve from experience. Pediatric Palliative Care teams may know doulas in your area. They can also be found in website searches locally by individuals or in collaboratives with a team of doulas. The following trusted organizations can help with a doula search. You are in charge. Trust your intuition.

National End-of-Life Doula Alliance
End-of-Life Doulas A - M

National Home Funeral Alliance
View Our Directory - NATIONAL HOME FUNERAL ALLIANCE

Champions for Palliative Care

Jennifer Siedman, on behalf of
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A family's story about their journey with their child is central to everything Courageous Parents Network (CPN) does. These stories help other parents feel they are not alone and find guidance. They help clinicians better understand the lived family experience—beyond the hospital setting—and the whole family's psychosocial and emotional needs. They are also the vehicle by which CPN promotes palliative care as an extra layer of support for families affected by serious illness.

CPN originated in the personal story of a rare disease mom, and now bereaved parent, who began advocating for pediatric palliative care and the needs of families shortly after her daughter's death from infantile Tay-Sachs. Recognizing the power of a parent's story to help others and harnessing her professional skills in television production and distance learning, Blyth Taylor Lord then began interviewing other families and producing their stories to digitally share. CPN's resources—video and podcast interviews, educational guides and webinars, presentations, parent-generated blogs, and a clinician portal—are grounded in parent and clinician voices that illuminate and share the lived family experience. The goal: to give parents and other caregivers confidence that they are doing the best they can for the child and family.

While Courageous Parents Network's growth has been steady, it has been limited by the size and capacity of the three-person team to advocate among clinicians and patient organizations for the family experience and palliative care. This advocacy has three parts: (1) representing families and their struggles and hopes; (2) increasing awareness and understanding of the value of pediatric palliative care; and (3) directing clinicians and patient organizations to CPN educational resources that promote "palliative-aware" skills. In 2023 to extend and scale CPN's impact, CPN recruited its first class of Parent Champions.

The Parent Champion Program has three primary goals:

- Cultivate a new generation of parents skilled at communicating the value of pediatric palliative care to non-palliative providers and patient organizations serving seriously-ill children and their families;
- Strengthen stakeholder knowledge of palliative-informed care;
- Engage new institutional and individual users in our network

CPN received 24 applicants from across the country. After a rigorous schedule of interviews, six Parent Champions were selected representing different geographic areas and diseases; both pre- and post-natal diagnosis; some whose children benefit(ed) from palliative care, others who after learning about the value of palliative care wished it had been part of their care journey. The group attended a three-day training in Boston where they explored CPN's core concepts; guidance on utilizing the resources found on both Courageous Parents Network and NeuroJourney in presentations and advocacy speaking training from Living Proof Advocacy.

About the 3-day intensive training one Parent Champion remarked, "I remember sitting at Blyth's table the first night in Boston as we went around the table sharing our six words, and my eyes filled with tears. Here, from all over the country, were moms like me. This group was one of the best gifts I have received." And another remarked, "This may not have been a goal of the program, but the camaraderie with other parents provided a unique kind of comfort and support that I haven't found elsewhere."

Figure 5: The six parent champions at training with Blyth Lord, Jennifer Siedman, Amy Graver, and Liz Morris.

Each Champion was assigned a staff mentor—Blyth Lord, Chrissy Salley, or Jennifer Siedman—with whom they met monthly. The Parent Champions also met monthly as a group for continued education—reviewing research CPN has participated in, sharing presentations they were planning, and supporting one another as friends and colleagues. Collectively by the end of their 16-month term, the Champions had given twenty-two presentations, equally split between clinician groups and patient organizations. Nine of the presentations were given at in-person professional or family conferences; successfully realizing the goal of expanding CPN's capacity to promote palliative-informed care to key audiences across the country and deepening the community of parents who make up the CPN network. Presentation content varied with focus on CPN resources, the benefits of pediatric palliative and palliative-aware care, and insights from parents' unique experience (e.g., NICU, bereavement). Both formal and informal feedback reinforced what we know to be true—that elevating the family experience directly from the voices of experienced parents both inspires and educates other parents and clinicians on the shared journey of caring for children with medical complexity.

Reflecting on the experience, the initial class of Champions captured the depth of impact:

> *"While my PC year is coming to an end, I feel like my advocacy on behalf of pediatric palliative care is just beginning. My work over the past year has opened doors and created opportunities to continue to tell my story."*

> *"CPN gave me training and a roadmap to do exactly what I feel called to do—help other families and clinicians caring for babies and children living with serious medical conditions."*

With the success of the pilot program, CPN has just completed the application cycle for the second class of Champions. We received over 60 applications, from three different countries. Four fathers submitted applications and several of the applicants are clinicians who are also a parent to a medically complex child. In every application is a story unique to each of the applicants themselves, but all reflect a strong desire by parents—often isolated by their circumstance—to bring their hard-won wisdom to other parents: to help empower and equip them, to bring them into community, and to make them feel less alone.

The Parent Champion Program, including the stipends the Parent Champions receive, is funded by grants; the first class with a grant from Sanofi, and the incoming 2025 class with a grant from the Ilene Beal Charitable Foundation. If your organization would like to schedule a presentation featuring a CPN Parent Champion, please email us at connect@courageousparentsnetwork.org.

Bridging the Gap in Pediatric Hospice Care: A Community Bridge of Support Through the Pediatric Hospice Tape

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Pediatric hospice care is a vital service that provides essential support for children with life-limiting illnesses and their families. Unfortunately, not all pediatric palliative/hospice patients have access to providers trained in pediatric palliative care and many other healthcare providers often feel unprepared when faced with the complexities of pediatric care, mainly due to a lack of experience and resources. This gap can lead to anxiety for both providers and families during critical moments. In response to this challenge, I developed the Pediatric Hospice Tape—a quick reference tool designed to streamline care for pediatric hospice and palliative patients. This article outlines the journey of creating this tool and its impact on community support for pediatric hospice care.

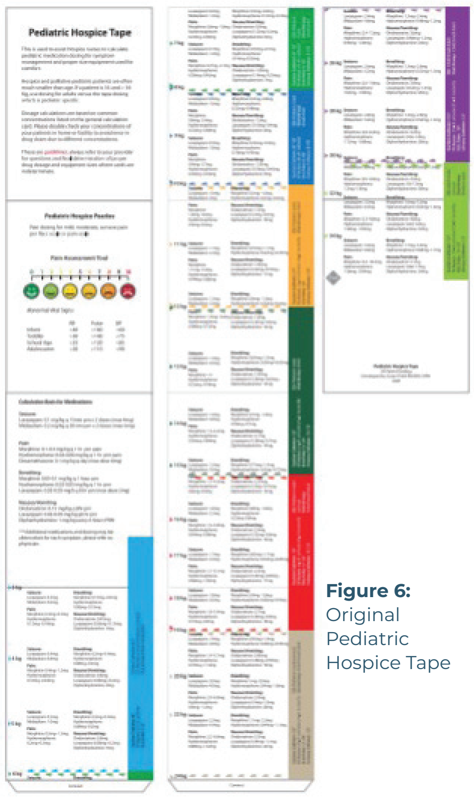

Figure 6: Original Pediatric Hospice Tape

The Challenge in Pediatric Hospice Nursing

My journey in hospice nursing began 14 years ago. Early on, I noticed a troubling trend: approximately 90% of our team members hesitated or "froze" when asked to care for a pediatric patient. The unfamiliarity and emotional weight of pediatric cases often resulted in uncertainty, which could hinder the timely delivery of care. This realization drove me to find a solution—a resource that healthcare providers could easily access to empower them to deliver compassionate and effective care without the overwhelming anxiety that often accompanied these situations.

The Development of the Pediatric Hospice Tape

In 2021, I developed the Pediatric Hospice Tape as a practical resource for healthcare providers, including MDs, nurse practitioners (NPs), and nurses working in various settings—field, inpatient care, and call centers. The original version was a foldable poster board tape, portable enough to fit in pockets or backpacks.

Features of the Pediatric Hospice Tape

- **Medication Guidance:** The tape provides common hospice medications for symptom management, including quick dosing ranges based on the child's length and typical sizes of supplies needed for hospice care, such as Foley catheters, nasogastric tubes, oxygen masks, and cannulas.
- **Ease of Use:** The design allows providers to measure a patient's length quickly and reference the appropriate dosing for medications. This facilitates clear communication between the provider at the bedside and the physician or specialist on the phone, who can refer to the same tape for alignment on patient care.
- **Starting Point for Dosing:** While the tape does not replace the need for accurate weight measurements, it serves as a reliable starting point, significantly reducing panic and uncertainty when encountering pediatric patients.

Impact and Distribution

After distributing the Pediatric Hospice Tape to nurses, NPs, and MDs across various capacities, we observed a remarkable shift. There was an immediate decrease in anxiety and confusion when responding to requests for pediatric care. Providers felt more empowered, knowing they had a practical tool at their fingertips.

Expanding Use to EMS

In 2022, we shared the Pediatric Hospice Tape with our ambulance service for transporting pediatric hospice patients. This integration allowed EMS personnel to reference the tape for medication orders during transport, ensuring continuity of care throughout the patient journey.

Figure 7: Newest Version of Pediatric Hospice Tape

Continuous Improvements

In 2023, we updated the Pediatric Hospice Tape to reflect the latest recommended dosing of medications and distributed it to our hospice affiliates. By 2024, we revamped the design into a durable, wipeable roll-up tape, making it even more user-friendly. Presenting this updated version at the NHPCO conference in Denver generated significant interest from attendees, including those running palliative clinics and rural pediatric providers seeking quick reference guides.

Community Support and Future Directions

The Pediatric Hospice Tape is a testament to the impact that well-designed resources can have on bridging the gap in pediatric hospice care. However, its development is just one part of a larger effort needed to improve care for pediatric hospice and palliative patients.

Bridging the Gap

1. **Comprehensive Training:** Continued education and training for healthcare providers are essential. Tools like the Pediatric Hospice Tape can complement ongoing educational efforts, ensuring that all team members feel equipped to provide care.
2. **Community Engagement:** Engaging local communities to raise awareness about pediatric hospice services can help foster a supportive environment. Organizations can collaborate with schools, businesses, and healthcare systems to educate families and providers about available resources.
3. **Advocacy Initiatives:** Advocacy for improved pediatric hospice services in rural areas is vital. This includes lobbying for policy changes that enhance access to care and support for families in need.

Conclusion

Creating effective tools and resources, such as the Pediatric Hospice Tape, is crucial in addressing the gaps in pediatric hospice care. By empowering healthcare providers with user-friendly references, we can reduce anxiety and enhance the quality of care for pediatric patients. As we continue to improve this tool and expand our community support initiatives, we strive to ensure that every child with a life-limiting illness receives the compassionate care they deserve—whether at home, in schools, or within their communities. Together, we can bridge the gap in pediatric hospice and palliative care, fostering a nurturing environment for both patients and their families.

Figure 8: The Pediatric Hospice Tape Package

If you would like more information about how to obtain the Pediatric Hospice Tape for your community, please send email to: sfinke@care4denver.org

I Want to Go Home: The Role of Palliative Care Transport

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Abstract

Palliative care transport allows critically and terminally ill children, who are receiving life-sustaining treatments, the opportunity to return home for end-of-life care. This intervention offers an alternative to hospital death, even for patients too ill to travel by private vehicle. However, there are system barriers to establishing a palliative care transport program. This article reviews the benefits, barriers to implementation, and the policy framework developed at Children's Mercy Kansas City. We also share our experience with the challenges and successes of our palliative care transport program.

Introduction

Palliative care transport is a specialized program specific to the transfer of critically and terminally ill children receiving life-sustaining treatments, such as ventilation or vasoactive medications, from a hospital setting to their homes for end-of-life care. The implementation of such a program presents challenges within healthcare systems, particularly in terms of awareness, logistical coordination, and institutional support.

At Children's Mercy Kansas City, a dedicated "Palliative Transport" team has provided this service to more than 50 patients over the past 12 years. These patients represented a range of diagnoses and required various levels of support and technology during transport and at home. This article explores the significance of palliative care transport, the barriers to its adoption, the specifics of the Palliative Transport policy at Children's Mercy, and the lessons learned from our experience.

Benefits of Palliative Care Transport

Research consistently shows that many families, when given the choice, prefer for their child's death to occur at home. When an option, home deaths are associated with better end-of-life experiences including improved symptom control, increased privacy, and a decrease in the cost of care compared to death in a hospital setting. Studies also demonstrate that children who die at home experience less emotional distress, and families report greater satisfaction with the care provided.

End-of-life at home can allow families to be fully present with their child in a familiar and private space. This setting provides families the freedom to grieve and manage the end-of-life process without the constraints of hospital rules and environments. For many families, it offers a sense of autonomy in a situation where they may otherwise feel powerless. Being in the home environment may allow families to honor cultural and spiritual practices that are integral to their grieving process. For these families, the palliative care transport becomes not only a medical service but also a cultural and spiritual accommodation.

Barriers to Palliative Care Transport

Despite the benefits of a palliative care transport program, there are significant barriers that hinder its widespread implementation. These barriers can be categorized into systemic, patient-specific, logistical challenges.

1. **Systemic Barriers**
   Healthcare systems may lack the necessary infrastructure or support for palliative care transport programs. Such programs require a robust and well-integrated palliative care team and a well-staffed transport team. They also require the institution to have a philanthropic attitude, as these transports may not be reimbursed by insurance.

2. **Patient-Specific Barriers**
   There is a "Goldilocks Zone" for the patient to access palliative care transport. Patients need to be sick-enough to not be able to travel by private vehicle and not so-sick that they are going to die in the coming hours (on the transport). Furthermore, there are some levels of life-sustaining treatments that cannot be provided within a transport vehicle and some distances from the hospital that are not reasonable to travel.

3. **Logistical Barriers**
   Once the decision to transport is made, logistical challenges arise. Some of the logistics considered include:
   - Mode of transport
   - Medical equipment and medications for enroute and home
   - Home accessibility and safety
   - Hospice availability
4. **Regulatory Barriers**
   Both the transport team and the hospice team have regulatory standards that may impact palliative care transport options. Some of the considerations to anticipate include regulations regarding transport personnel, medical equipment, and resuscitation requirements. Furthermore, ensuring that the care team complies with state licensing requirements and medical regulations, such as EMTALA (Emergency Medical Treatment and Labor Act), is critical to ensure safe and legal transport.

Palliative Transport Policy Development at Children's Mercy Kansas City

The creation of a formal policy for palliative transport requires broad institutional support. At Children's Mercy Kansas City, the Palliative Transport Policy was developed through collaboration of the Palliative Care Team (PaCT) and the Children's Mercy Critical Care Transport (CMCCT), along with stakeholders from the inpatient units, legal counsel, and external agencies.

The policy developed at Children's Mercy includes the following key components:

1. **Eligibility Criteria**
   The first step in our policy was to define the patient population that would benefit from palliative transport. This includes children who are unable to travel by private vehicle and whose condition is "stable enough" for transport and who have agreed to a Do Not Resuscitate plan of care during the transport and once at home. Patients requiring life-sustaining treatments, such as mechanical ventilation or vasoactive medications, are eligible for the service, though if we believe the risk of death during the transport or in switching equipment is significant, we discuss this with the family to ensure transport is the right choice for them. Candidacy criteria are important to ensure patient safety and appropriate resource allocation.
2. **Transport Coordination**
   Coordination between the medical team, critical care transport team, and home hospice team is critical to ensure a smooth transfer. Our policy includes protocols for scheduling transport (>24hours notice), ensuring appropriate medical equipment, and confirming the readiness of the home environment. We also set guidelines for the transport distance, limiting the one-way distance to about 175 miles (round-trip 350 miles), ensuring the transport team can safely manage the transfer within available shift hours. Prior to the transport we ensure a hospice

agency is available to meet us at the home so there is a direct handoff of the medical care providers (mirroring a "facility to facility transfer" at the home). We also ensure that a 3+ day supply of medications is filled at the hospital outpatient pharmacy and available for use in the transport and once home.

3. **Staffing and Safety Protocols**
   A "full" CMCCT includes an emergency medical technician, a critical care nurse, and a respiratory therapist. One member of PaCT travels with the patient and CMCCT; this is either the patient's primary PaCT nurse or a physician member of the team (depending on the risk of death enroute). All members of PaCT complete an annual transport safety training.

4. **Patient and Family Communication**
   Open communication with families is vital throughout the transport process. Families are provided with clear information about what the transport process entails, what to expect upon arrival at home, and the role of the home hospice agency. One family member may accompany the patient on the transport and others are invited to follow in their private vehicle. We provide anticipatory guidance that should the patient show signs of actively dying, we will pull over to the side of the road. Whoever has been following us in the family vehicle can climb into the ambulance with us, and we will ensure it's a sacred space and comfort is provided. Per the policy, we would continue the transport to the home, and the hospice team would support the remaining aftercare with the family.

Lessons Learned and Impact of Palliative Care Transport

Since the implementation of our pediatric palliative transport program in 2012, we have facilitated 57 transports, 55 by ground transport and 2 by fixed-wing air transport. These transports have included children of various ages (weeks old to teenagers) and diagnoses. About one-quarter of the transported patients died within 48 hours of returning home, while a couple of others ultimately chose to return to the hospital for inpatient care when they outlived the expected prognosis (one patient actually had two transports years apart!).

While the quantitative outcomes of palliative transport are challenging to measure, the qualitative benefits are clear. Families often report a profound sense of relief and peace after returning home. Being able to die in a familiar environment provides families with emotional and psychological comfort, which may not be replicated in a hospital setting. The decision to die at home is, for many families, as important as any medical intervention. It offers a sense of agency and control during a time when most decisions are beyond their influence.

Conclusion

Palliative care transport is an essential service that provides critically ill children and their families the opportunity to die at home, surrounded by loved ones. Despite the challenges in its implementation, including systemic, logistical, and patient-specific barriers, palliative care transport offers profound benefits. The Palliative Transport Policy developed at Children's Mercy Kansas City serves as a model for creating safe and effective palliative care transport programs, ensuring that families have access to the compassionate end-of-life care they deserve.

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Family Certified Nursing Assistant/Home Health Aide Program

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The worsening nursing shortage is having a devastating impact on private duty nursing (PDN) services, particularly for pediatric patients and their families. Many parents—especially mothers—are forced to leave their careers to provide complex, round-the-clock care for their children. This level of caregiving extends far beyond the typical parental role.

Since 1999, eight states (CO, AZ, FL, IN, NC, MA, PA, and NH) have allowed parents and family members to become state-certified caregivers through equivalent programs to certified nursing assistants (CNAs). Through delegation, these trained aides can perform skilled tasks such as tube feeding and medication administration, supplementing PDN provided by RNs or LPNs. This model is referred to as the Family Certified Nursing Assistant (FCNA), Family Home Health Aide (FHHA), or Complex Care Assistant (CCA), depending on state terminology. Some states have even established a new discipline, such as the CCA, to differentiate this model from standard home health aide services.

Four additional states (MT, IL, NJ, and ME) have passed legislation to integrate this model into their PDN benefit and are in the process of developing regulations. Several more states are actively considering or have pending legislation for implementation.

The model discussed here applies specifically to PDN clients, not to Personal Care Services (PCS). While 26 states have permitted parents and family members to provide PCS for qualifying minors since COVID-19, this article will not focus on that aspect. It is important to distinguish that FCNA services are not the same as PCS.

While the FCNA model is not a standalone solution to the nursing shortage, it provides families with an additional choice, ensuring their children receive care while broader efforts continue to address workforce challenges.

Lessons from Other States

Team Select Home Care and other providers operate in multiple states where these programs have been active for decades. Colorado pioneered this model in 1999, driven by a mother advocating for Medicaid reimbursement while caring for her medically fragile child without reliable nursing support. Her efforts laid the foundation for today's "Parent CNA" program, which now serves over 5,000 families annually.

In Colorado, the program has expanded to include both skilled and unskilled medical care needs. Medicaid allows delegation of skilled tasks such as tube feedings, and agencies provide free training for family caregivers. For families, this program has been life-changing, offering parents the opportunity to receive compensation for caregiving while becoming fully trained professionals. Many families rely on this support after losing jobs due to their child's care needs. Additionally, the model benefits the healthcare system by freeing up professional nurses to focus on patients requiring higher levels of medical care. This creates a win-win situation: families receive the care they need, and nursing resources are more efficiently allocated to those with acute conditions.

Program Impact on Care Continuity

Based on Team Select's internal data, this model has led to hospitalization rates 90% lower than the national average, underscoring the critical role of stable, trained caregivers in maintaining health at home. The reasoning is simple: children authorized for home health nursing are fragile but stable, and maintaining their stability requires consistent, reliable care from trained caregivers. Family members—who never miss a shift and understand their child's needs better than anyone—play a crucial role in this continuity of care.

Legal and Operational Considerations

One concern frequently raised by providers relates to medical liability. In states where this program is implemented, medical liability incidents are rare—often lower than in traditional PDN-only care. Families who participate in the program value the opportunity and comply with all necessary regulations, minimizing risks for both families and agencies.

As providers, Team Select Home Care and others expanded this program beyond Colorado about six years ago to address staffing shortages in PDN, particularly exacerbated by the COVID-19 pandemic.

Clarifying Common Questions About the Program

A common concern is whether PDN agencies are required to participate in the FCNA model. Participation is entirely optional. Agencies can offer this program or continue with other home care models, such as personal care services, hospice care, and/or Medicare Home Health services. Agencies retain the flexibility to determine whether to integrate the FCNA model into their offerings.

Participation in this model is also voluntary for families. Many states with this program have statutory language ensuring participation is optional, protecting families from being forced into it unless they willingly opt-in.

Training in most states is provided at no cost to the family and is funded by the home health agency. There are no limits on how many FCNAs an agency can train. Typically, the child's parent identifies who they want trained on their case, and the agency facilitates the training. In most states, FCNA training results in certification rather than licensure. While this article uses the term FCNA broadly, most states classify the role as equivalent to an HHA rather than a CNA, which is a licensed discipline. Importantly, in most states, agencies cannot charge families for training, even if the caregiver later transitions to another agency. Agencies recoup their investment by ensuring consistent staffing and care delivery.

To qualify as an FHHA, caregivers must meet essential criteria. They must be over 18 years of age, be a family member or eligible relative, and complete an approved training program. Additional requirements typically include passing background screening, obtaining CPR certification, and fulfilling 12 hours of annual in-service training.

Training requirements vary by state, ranging from 75 to 160 supervised hours under an RN with specialized experience. While most states do not allow testing outside of training, Massachusetts provides this option. Depending on the patient's needs, as state regulations permit, caregivers may also need additional training for specific skills.

Moving Forward

As more states implement this model to expand care options for PDN families, agencies like Team Select Home Care continue to support these efforts. The Centers for Medicare and Medicaid Services (CMS) endorsed paid family caregivers for personal care in June 2023, and the American Academy of Pediatrics included this model as a state advocacy priority in November 2024. With continued collaboration, we hope more states will adopt this model—empowering families, alleviating the nursing shortage, and ensuring medically fragile children receive the care they deserve.

Grief Camps for Bereaved Children: An Indiana Hospice Organization Perspective

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Grief and bereavement are a normal aspect of life. Over three-fourths of children experience some form of adversity, which includes the loss of a parent or sibling, which may lead to grief over their situation (Luecken, p. 1). Parental loss is as high as an estimated 4% of children under the age of 18 in the U.S. Furthermore, many children will lose a sibling, which increases their risk of demonstrating later behavioral problems, enuresis, headaches, abdominal pains, depression, fear, or poor school performance (Creed, p. 2). Bereavement camps are now prevalent throughout the States in order to help children deal with the feelings connected to the loss of a loved one. The Center for Hospice Care, in Mishawaka, IN, is one such organization that assists children through their sponsored Camp Evergreen Program.

Hospice Provider Case

An ex-36-week twin female who was initially thought to be developmentally appropriate was given a post-natal diagnosis of hypoxic ischemic encephalopathy (HIE) and cephalomalacia. Both of these complications were associated with Twin-Twin Transfusion Syndrome. The patient was subsequently further diagnosed with bilateral cortical blindness, seizures, and neurologic impairment. Her seizures remained resistant to adjusted antiepileptic dosing and efforts to utilize both occupational therapy (OT) and Developmental and Behavioral services (DB) for her poor tone and spasticity issues were unsuccessful.

The patient presented to the Center for Hospice at two months of age in order to receive pediatric palliative care. She demonstrated severe hypotonia, head lag, and intermittent LE myoclonic jerking. A short-acting benzodiazepine was added to her long-acting medication, and her care was followed for approximately five months while further adjustments were made to maintain symptom control and to alleviate any suffering that she developed. Her weight that had once remained stable eventually decreased during the later stages of her treatment, and she exhibited increased seizure activity.

By eight months of age, she received a Ventriculoperitoneal (VP) Shunt that ineffectively addressed her elevated intracerebral pressure (ICP). She received a final neurology visit at that time that demonstrated no neurological improvement had been achieved, since her initial shunt placement took place, and the parents appropriately requested that the patient begin hospice services in order to maximize her quality of life (QOL). She was followed for an additional month and then was eventually admitted to the organization's inpatient unit (IPU) and peacefully passed away within five days at approximately 13 months of life.

The focus that was once given to the child was now directed towards meeting the needs of both the mother and her then 6-year-old brother both of whom were now bereaved. The family was referred to the Center for Hospice Care Bereavement Department and the mother eventually participated in a parental workshop for parents which addressed the loss of their own particular children. The brother was invited to a particular Camp Evergreen Program for younger children to help cope with the loss of his sibling.

The Impact of Childhood Bereavement

Dealing with the loss of a loved one is difficult for everyone, including children, which can lead to a profound emotional crisis (Lueken, p. 2). Although most children will progress though a normal grieving cycle and return to a healthy baseline without significant impairment, it is important to note that some do not. In the short term, children may demonstrate psychological distress, such as increased aggression, sleep disturbance, and overall difficulty managing their routine activities. However, children may progress and eventually demonstrate lifetime psychological impairment. Children are also at risk for potential physical consequences particularly if they suffer a loss before the age of 16. The early exposure may lead to the potentiation of cortisol levels that can elevate overall blood pressure and have an effect on their sense of well-being (p. 3).

Feelings and emotions associated with death may surface at varying degrees and intensity. Addressing the feelings and understandings of children in a non-linear manner can help to alleviate both physical and psychological consequences (Brown, p. 78). Bereavement (grief) camps emerging throughout the country provide one outlet to meet the given need. Their overall mission is to encourage attendees to express themselves in whatever manner they would like, while introducing fun activities. This may take place either over an extended weekend or during a one-day event. Camp staff are selected and encouraged to provide support to the participants throughout the process and fulfill distinct roles.

Although these camps are thought to benefit those who are bereaved, little research exists to support that understanding. Nevertheless, one study performed in the Pacific Northwest supported the notion that bereavement camps are successful in that they help to provide connection between members of the assigned groups. One participant mentioned that what is gained is "the validation that you're not, you know, a 'weirdo', you know, this outcast. That there are other people who have shared an experience like this" (p. 83). Furthermore, bereavement camps allow the same participants the independent space to experience individual grief and find their own path. Children express their need to individually pursue their healing and acknowledge that "there is no one complete 100 percent thing you can say about the process of grieving. There's no complete way you can place grief in a box and say this is what happens" (p. 84).

Center for Hospice Grief Camps

Center for Hospice Care's bereavement program in the South Bend, Indiana, region offers an array of services to families coping with the death of a loved one. Camp Evergreen is one of the programs that is offered specifically to youth and teens that have experienced the death of a significant person in their life. Camp Evergreen started in 1994 and has served 1,080 individual youth and teens and 45 parents/guardians since that time. Camp Evergreen offers two camps annually. Both camps are one-day camps that occur on a Saturday. There is a camp in the early summer that serves youth and teens 10-18 years of age and is provided off site to include several traditional camp activities (swimming, boating, archery, etc.) along with the grief work. The other camp is done in the fall season and happens at one of the Center for Hospice Care offices.

Both camps separate the campers into groups according to their age. Camp Evergreen as a whole utilizes volunteers to provide direct support to the campers throughout the entire day. The volunteers themselves have experienced their own losses and are able to provide a level of empathy to each camper.

There are several goals that Camp Evergreen strives to meet with the participants. One goal is to decrease isolation and normalize grief, which is a difficulty that has been identified by youth and teens that have attended camp. The bereavement staff counselors utilize their counseling skills to provide education on the grieving process, typical grief reactions, and ways to cope with the grief reactions that present. The campers have the opportunity to tell the story of their loss. Both camps have opportunities for fun and friendship.

Camp Evergreen ends each camp with a ritual of remembrance utilizing the evergreen tree. The evergreen tree stays green all year. When needles die and fall to the ground, new needles take their place. The needles that fall to the ground help nourish the tree and become a part of it again. The evergreen tree is a good example of life and death.

The family which was referenced in the case study attended several separate services including the Camp Evergreen family workshop which is the camp that happens in the fall. This family workshop started in 2018 with the intention of bringing the parent/guardian into the camp experience. This allows for support through joint activities and separate activities. Furthermore, the workshops are able to provide support to adults that are in the child's life, as well as to any other affected child. Because grief impacts the family unit, this is one way to support the family unit as a whole.

In addition to camp programming, Center for Hospice Care bereavement services are committed to giving a variety of other options to help support bereaved family members. For instance,

Figure 9: Ella and her mother Mary

bereavement services continue to support the mother and the 6-year-old brother of the patient long after the completion of their camp visit. The mother receives individual counseling and participates in a personalized workshop designed to serve parents that lost a child. This was a Saturday workshop developed to fill an identified gap in the service area.

Loss specific groups/workshops have received positive feedback and are considered beneficial by the attendees afterwards. For instance, specific feedback was gathered via phone calls from the above-mentioned mother of the deceased child. She shared that the support she received surprised her in that she first thought the workshop would only enable her to have the opportunity to meet other parents who had lost their own child. However, she later discovered the further benefit of learning more about the child's long-term illness process. For instance, one other family shared how the process enabled them to address any future difficulties they might face, which empowered their decision-making afterwards. The mother also demonstrated appreciation for the presence of the hospice physician during the Saturday workshop. She shared that she received much comfort that derived from having the provider as a part of the support workshop. She also provided feedback regarding her son who attended the in-house Camp Evergreen session. She expressed that her son who often has difficulty interacting with others was able to make positive interactions with the adult with whom he was paired. She expressed that the information he learned at the camp continues to provide opportunities for later conversations at home. There is an overall appreciation from all of the services that continues to help her through her current grieving process.

As a side note, another particular teenager shared her story about attending an earlier summer camp. Initially, she wasn't sure about attending Camp Evergreen. The Life Transition Center staff spoke with the teen's mother several times and each time the daughter felt more comfortable with the idea of attending, which she did one week later. At the camp site, she repeatedly thanked staff members for allowing her the benefit of the camp experience. She shared on her evaluation how supportive everyone was and that she liked the fact that she didn't know anyone going in as it provided a clean slate. Just one of many stories pointing to the impact of Camp Evergreen!

Lastly, the Center for Hospice Care through the life transition center continues to follow up with the families after the completion of the camps. The forementioned mother receives personal grief counseling and continues to update the staff regarding the brother's current situation. The camp only lasts for one day, but the care lives on afterwards.

Conclusions

Positives:

There are several positives that come from the grief camp that Center for Hospice Care provides. Youth and teenagers are able to meet others that have their own losses, which helps to share a sense of support and commonality. Also, the follow-up process provides a continual understanding that those who grieve are not alone.

Negatives:

There are some pitfalls that come with the camps we provide. Some of the families feel disconnected at times when the other family members do not have similar stories to share. This can lead to a feeling of awkwardness. The camps do their best while attempting to assign participants in groups with members experiencing similar situations. However, despite this effort, it is not always possible for those that register.

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Partnership with Funeral Professionals in Supporting Families & Their Communities When A Child Dies

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Pediatric palliative care practitioners often have the unique honor and responsibility of supporting children and families through the full trajectory of their illness. Despite the usual practice in medicine of care ending after end of life, this should continue even after death. Families would benefit from continued guidance and support with the steps immediately after death. They may find themselves asking what now? What next? They are suddenly faced with many decisions around post-mortem care and bereavement rituals. Palliative care teams can make this journey just a bit easier by increasing their familiarity with the funeral and burial process and building relationships with their area funeral professionals.

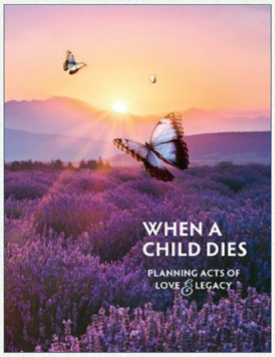

Figure 10: Cover of When a Child Dies Booklet

From the initial phone call to navigating the emotional & complex responsibility of guiding a family following the death of a child, funeral professionals offer a unique touch point of support, education, and advocacy for grieving families. Funeral home staff often shape the last moments and memories a family has of their loved one and provide the community with a chance to participate in grieving.

"We dressed Sophie as a fairy with her tiara and wand. We put into her casket her doll, favorite blanket and letters from her brothers"

We are honored to share with you When a Child Dies: Planning Acts of Love & Legacy, a free resource that offers guidance, inspiration, and decision-making pathways to help families with the funeral process. The booklet is part of an innovative partnership with the Funeral Service Foundation (FSF), the National Funeral Directors Association (NFDA), Pediatric Palliative Care Coalitions (PPCC), and bereaved families to develop educational guidelines, identify resources, and build strategies to improve the experience. A highlight of the spirit of this resource is that it was built from voices of parents, healthcare providers, grief specialists, and funeral professionals, all who graciously contributed their stories and expertise in developing it.

Common themes in the interviews and surveys during development were identified and guided the design and structure. These insights included the importance of personalizing the service to represent the uniqueness of each child, dedicating more time for emotions and processing service decision-making, awareness and support for staff processing and self-care. Most importantly, parents repeatedly expressed desires for the funeral staff to "be curious" and ask us about the child that was being memorialized, listen to the stories, and bear witness to the pain. The other desire families asked of funeral staff was to "be creative." Think outside the box and recognize the role of nontraditional choices. Remind parents that there are ways they can continue to love and care for their child. Consider both "in the moment" modeling child-sensitive, family-centered care, while also establishing meaningful partnerships that facilitate a funeral home's confidence and ability to compassionately care for families. Remember that caring for a family after the death of a child is also emotionally difficult for funeral professionals.

Our findings identified important points in the funeral planning process to emphasize working together with families as they plan end-of-life rituals and prepare to say goodbye to their children.

- Transfer of Care
- Preparing the Body
- Planning the Service & Final Resting Place
- Memory Making & Legacy Building
- Sibling & Youth
- Grief Support
- Collaboration & Community

Transfer of Care:

Figure 11: Photo of a funeral procession with child coffin

Families consistently reiterated the importance of this moment and the physical separation from their child. While institutional policies can be cumbersome, and the location may determine and limit many of the decisions, consider how you advocate for the family, ways in which the family can be involved, and explore rituals that facilitate making their last moments intimate and sacred. Whether death occurs at home, at the hospital, or it involves the coroner, talk through this process with the families. Normalize the parents' wish to hold, bathe, and dress their child or even read a book or play their favorite music during this time. As always, inquire and respect cultural or religious practices. The booklet shares many ideas about how to help facilitate the transfer of care.

"Love cannot be measured in money. A more expensive funeral does not mean a better funeral."

Be mindful of the family's experience and what they witness. Feedback has included many families recounting distressing visual memories of their child being placed in a cardboard box or plastic bag. If it is a home death, communication should include anticipating the importance of "child-appropriate" equipment such as a bassinet, car seat or using a favorite blanket or team flag to wrap the child. It could be important to facilitate the

Figure 12: Picture of young girl putting flowers on coffin at gravesite

> **“Explore sharing the cost of a cuddle cot or Moses basket with your area funeral home”**

parent carrying or accompanying the child to the morgue or funeral transportation. Offer the opportunity to have a favorite blanket, toy, or stuffed animal to accompany the child. It should be clarified if the family expects this to be returned. If the coroner is involved, call to request permission for legacy activities or coordinate with the funeral home an opportunity to do legacy work once the child is released. Attempts should be made to save any clothes, blankets, jewelry, or personal belongings and allow the family to determine what to keep.

Preparation of the Body:

Including the child’s favorite shampoo, lotion, perfume, or make-up can help bring comfort and familiarity to the family if they desire this. If there is an implanted device, you may want to discuss with the family if they want it removed or stay in place. Photos can also serve as a frame of reference in preparing the positioning of the child to look like themselves. It is important to remind families that even if there was an autopsy, an open casket is still an option. Or if the family chooses cremation, they can still host a service or gathering.

Planning a Service and Final Resting Place:

There is no way for a parent to truly feel prepared for planning a child’s funeral. While there are endless possibilities, the goal is to offer a service that meets the needs of the family and reflects the essence of their child. Cost can be a significant stressor for families. It can be helpful to familiarize yourself with local resources including funeral homes and crematories that may donate or discount their services. Cemeteries often donate plots or designated areas for infants and children. Additionally, foundations and community organizations often provide financial support for funeral and burial costs.

Figure 13: Pallbearers dresses as super heroes

When appropriate having team members accompany the family to planning meetings can be helpful. It can also be helpful for them to identify their "helpers." It is also important to empower them to make boundaries with well-intentioned family and friends and recognize the final decisions are theirs. Assistance in guiding siblings and other children through the first viewing can be meaningful. Having staff trained to help them understand what to expect during the service, and highlighting ways to participate can facilitate their inclusion.

Families have shared amazing stories of superheroes, fairy princesses, firetrucks, and big wheels featured at their child's funeral. Beautiful stories including sunflowers, purple parties, teddy bears, banjos, and Blackhawks themes have highlighted the spirit of their child in the service. Extraordinary funeral professionals have shared stories of providing rocking chairs, baby cribs, bassinets, wagons, and even bean bags that create a service that is child-friendly and facilitates a comfortable space for remembrance. It is important for funeral homes to have child-friendly, child-sized options for caskets and urns. While no parent wants to google "child's funeral," there are amazing examples and options on websites such as Etsy. Families may also choose non-traditional sites such as local parks, zoos, their backyards, and gardens in addition to traditional services at churches or funeral homes as locations for the service. Services have included balloon releases, bubbles, kites, painting rocks, and scattering glitter or flower petals at the gravesite.

It is important to be mindful that more often families are requesting services for pregnancy loss. Many funeral homes provide special programming to memorialize these deaths and it may be helpful to also know these local resources.

Figure 14: Photo of a child's gravesite

Figure 15: Sibling at gravesite

"You may also need to guide the family in managing their child's digital legacy and presence on social media platforms such as Facebook, Twitter, Instagram, and TikTok."

Memory-Making & Legacy Building Activities

Palliative care teams are often rock stars at memory-making and legacy-building. Collaborating with funeral homes with shared expertise can make a significant impact. Most funeral homes only serve a small number of children each year, and often do not have access to child-appropriate materials. Additionally, they may not be versed in ways to include siblings and other children.

Grief Support

Families continue to need support and guidance throughout their grief journey. Many funeral homes sponsor grief support programming. This may be another opportunity to work together to build resources. For example, a grief support library and resource guide would be something meaningful for both a palliative care team and funeral home to build together. Several funeral homes shared they host annual memorial services or events for families in their community who have experienced a pregnancy loss or death of a child.


Figure 16: Pink and Blue Booties

Collaboration and Community of Care:

We encourage you to seek collaboration regarding end-of-life care by building relationships with your local funeral professionals. There is enormous potential to create healing opportunities in these collaborations. From gentle hand-offs between the hospital or home to the funeral professionals after death, to supporting legacy-building activities, to offering support for siblings and children attending a funeral and working together to identify grief support services the ground is fertile for opportunities. Hopefully, this guide serves to initiate the conversation.

"Coordinate with your area funeral home donated items such as knitted booties, caps, blankets, and infant gowns."

When a Child Dies: Planning Acts of Love & Legacy – Order **FREE** Copies

We are honored and humbled by the stories told, and the dignity of our funeral professional partners who serve grieving families with tenderness and compassion. We are grateful to the Funeral Service Foundation for funding this significant resource. Many funeral professionals have shared their own stories of loss and memories of families they carry in their hearts – sometimes even decades later.

James K, Hawley B, McCoy CR, Lindley LC. Challenges and Opportunities of Providing Pediatric Funeral Services: A National Survey of Funeral Professionals. *American Journal of Hospice and Palliative Medicine*®. 2022;39(3):289-294. doi:10.1177/10499091211019298

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Understanding Measles in Children: The Role of Hospice and Palliative Care

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Measles is a highly contagious viral infection that primarily affects children and can lead to severe health complications, even death. Despite the availability of a highly effective vaccine, measles has surged and continues to claim the lives of children worldwide (Roush, 2025), especially in areas with low vaccination rates such as Texas (Texas Health and Human Services, 2025). This reflection, assisted by OpenAI, explores how measles leads to fatal outcomes in children, and how hospice and palliative care can play a crucial role in supporting both the child and their family during such difficult times (OpenAI, 2025).

How Measles Can Lead to Death in Children

Measles, once considered a common childhood disease, has been largely controlled in many developed countries thanks to widespread vaccination. However, in the US it is emerging as a major public health concern.

The virus spreads through respiratory droplets, when an infected person coughs or sneezes. Symptoms typically start with a high fever, cough, runny nose, and sore throat, followed by the characteristic red spots on the skin (World Health Organization, 2024). While many children recover with no long-term effects, measles can lead to severe complications such as pneumonia, encephalitis (brain inflammation), and severe dehydration, all of which can be fatal (World Health Organization, 2024).

1. **Pneumonia:** Measles weaken the immune system, making children more susceptible to secondary infections like pneumonia. Pneumonia is one of the most common causes of death in children who contract measles, particularly in malnourished children or those with compromised immune systems.
2. **Encephalitis:** This serious complication occurs in a small number of children with measles and can lead to permanent brain damage or death. Encephalitis is an inflammation of the brain that can cause seizures, difficulty speaking or moving, and in some cases, coma.

3. **Malnutrition:** Measles can cause severe diarrhea and dehydration, especially in malnourished children. Dehydration, when left untreated, can quickly become life-threatening.
4. **Immune System Compromise:** The measles virus suppresses the immune system for weeks to months after infection, making children more vulnerable to other infections, which can complicate their recovery and lead to fatal outcomes.

In regions where vaccination rates are low, the number of children affected by measles—and the tragic outcomes associated with it—remain high. This highlights the importance of vaccination in preventing such deaths.

Hospice and Palliative Care: Providing Support for Children with Measles

When a child's measles infection leads to severe complications, and recovery is no longer possible, the focus of care often shifts from curative treatments to palliative care. Although hospice and palliative care clinicians can be at high-risk for occupational exposure (National Nurses United, 2024), there is an essential role for hospice and palliative care in improving the quality of life for these children and providing support to their families during an incredibly difficult time (Goi et al., 2022).

Managing Symptoms and Providing Comfort. Hospice and palliative care teams are experts in symptom management. In the case of children suffering from measles complications, these teams work to alleviate pain, control fever, manage breathing difficulties, and address other physical symptoms, such as dehydration. Their goal is to ensure the child is as comfortable as possible during their final days or weeks.

In children with encephalitis or other neurological complications from measles, palliative care can help manage agitation, confusion, and seizures, helping to reduce suffering and allowing the child to experience peace.

Supporting Families Emotionally and Psychologically. The emotional toll of losing a child to a preventable illness like measles is immense. Hospice and palliative care providers offer critical emotional and psychological support to the child's family, helping them navigate their grief, fear, and sadness. Palliative care teams include social workers, counselors, and chaplains who are trained to help families process their emotions and make informed decisions about care, including the decision to cease aggressive treatments in favor of comfort care.

Providing Care at Home or in Hospices. In many cases, families may choose to care for their child at home rather than in a hospital, where resources might be stretched thin. Hospice and palliative care teams can support families in this decision, providing medical supplies, pain management, and emotional care at home. This allows families to spend their child's final days in a familiar, comforting environment, surrounded by loved ones.

For families who choose to receive care in a hospice setting, the child will receive specialized attention that focuses on maintaining dignity and comfort. Hospices provide a calm and nurturing environment for both the child and family, offering respite care, bereavement support, and ongoing counseling.

End-of-Life Care Planning. One of the difficult, but important, aspects of palliative care is end-of-life planning. Care teams help parents and guardians understand what to expect as the child's condition progresses, giving them time to say goodbye and make decisions about funeral arrangements, organ donation, and other matters. This ensures that the family's wishes are respected and that they are prepared.

The Importance of Palliative Care in the Context of Measles

Hospice and palliative care are essential services when a child faces the end of life due to a severe illness like measles. While prevention through vaccination is the best way to protect children from measles, when a child succumbs to the disease, providing compassionate care for them and their family is paramount.

Palliative care ensures that children with measles and their families are supported in ways that go beyond just medical treatment, addressing their physical, emotional, and spiritual needs during one of the most challenging times of their lives.

The Way Forward: Prevention and Support

While the tragic loss of children to measles can be mitigated through widespread vaccination efforts (Vaillant et al. 2023), it's equally important to ensure that when measles does strike, there are systems in place to offer supportive, compassionate care. Expanding access to palliative and hospice services is crucial in alleviating the suffering of children and their families.

Parents and communities need to be educated about the importance of vaccination to prevent measles outbreaks. But for those who do face the consequences of the disease, knowing that hospice and palliative care services are available can provide some comfort during an incredibly painful experience.

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