

**ANNIVERSARY ISSUE**

ISSUE #75 | MAY 2024



# Pediatric e-Journal

**PEDIATRIC ADVISORY COUNCIL**

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



**NHPCO**

National Hospice and Palliative  
Care Organization

# Pediatric e-Journal

## Pediatric Palliative and Hospice Care

Issue #75 | May 2024

### Issue Topic: Anniversary Issue

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Welcome to the 75th issue of our Pediatric e-Journal. When we produced the first issue of our Pediatric e-Journal (then called the NHPCO Pediatric Palliative Care Newsletter, and later the ChiPPS Pediatric Palliative Care Newsletter/Journal), it is likely that we did not imagine we would still be delivering free, quarterly, electronic issues some 20 years later. But here we are thanks to NHPCO, to our growing list of readers, to our contributors, and to everyone who has taken part in the Workgroup that is the backbone of this project.

Each issue of this e-Journal typically is organized around a focal theme. In this anniversary issue, however, we have simply brought together an eclectic group of articles that illustrate many aspects of the breadth and depth of how pediatric hospice and palliative care has grown over the years. As you will see, articles in this issue range from: a newcomer's perspective to the views of very experienced clinicians in pediatric palliative and hospice care; from comments about the roles of bereaved parents in helping to educate caregivers to advocacy for the contributions of child life specialists and psychologists; from insights about the great value of respite care to the important roles of statewide PPC coalitions; from educational programs for nurses to the importance of grief care for PPC professionals, and to the development and maintenance of relationships between hospice programs and pay source stakeholders in concurrent care.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Hospice and Palliative Care Organization. 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 <https://www.nhpc.org/palliativecare/pediatrics/>

Comments about the activities of NHPCO's Pediatric Advisory Council, its 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 the next two issues to follow in 2024 and for those thereafter. Our tentative plan is to address social media, technology, and communications in Issue #76 and home care in Issue #77. If you have any thoughts about these topics or other subjects for future issues in 2025 and/or potential contributors (including yourself?), please contact Christy Torkildson at [Christy.Torkildson@gcu.edu](mailto:Christy.Torkildson@gcu.edu) or Melissa Hunt at [Melissa.Hunt@optum.com](mailto:Melissa.Hunt@optum.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 NHPCO Pediatric Council, or the National Hospice and Palliative Care Organization.

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### **A Note of Thanks** p. 4

*Ben Marcantonio, COO and Interim CEO of NHPCO*

### **A Newcomer's Perspective: What I Have Learned from Pediatric Palliative Care** p. 5

*Michaila Kaufman, BSN, RN*

When an experienced nurse joins a Pediatric Advanced Care Team she finds things different: "Evident on my first day, I found that pediatric palliative care (PPC) embodies a blend of clinical expertise and person-centered care, empowering patients and reducing suffering." In her first consultation, she "realized the most essential aspect of PPC is its unwavering dedication to knowing the individual beyond the illness, including their joys, fears, and aspirations" and she adds that, "One of the most important lessons I have learned since joining the PACT team is the profound significance of effective communication, and that words carry weight." Additional lessons make this a meaningful introduction to our issue.

### **I'm Feeling Hopeful. I'm feeling Anxious.** p. 7

*Blyth Lord*

In this article, the Executive Director of Courageous Parents Network, herself a bereaved parent and aunt, reflects on the 10th anniversary of CPN and the good work it has done as part of the growth of the field of pediatric palliative care. She takes note of the generous involvement of clinicians and the increasing appreciation of parents for how PPC can improve the lives of their children and families. At the same time, her anxiety arises from two trends: "The first trend is the fact that remarkable advances in medical technology are allowing more and more medically fragile children to live longer and longer," which has both advantages and disadvantages; the second trend is "the shortage of the home care nurses and personal care assistants who make it possible for families to care for these children at home." Still, she closes on a hopeful note.

### **Bereaved Parents as Educators of Clinicians: Reflections and Invitations for Continued Relational Learning within Pediatric Palliative Care** p. 9

*Dannell Shu*

This author is herself a bereaved parent and a long-time advocate for the role of bereaved parents in clinician education. In this article, she reflects on the role of the Initiative for Pediatric Palliative Care in fostering the roles of bereaved parents as advocates and educators. She also identifies four key factors for continued growth, each with action invitations.

**Palliative Care PR: Exploring New Message Strategies**

p. 14

*Jared Rubenstein, MD*

This article begins from the following premise: "[D]espite the call to start palliative care as early as possible, referrals to subspecialty palliative care often come much later than we would like. Not only does it seem like this messaging has not been enough to break the palliative care stigma among healthcare workers, there is now even data that clinicians often project palliative care stigma onto patients and their families! There also continue to be calls to rename our field because 'palliative care has an image problem.'" If these premises are correct, what should we do? This author suggests drawing on the robust body of literature demonstrating the benefits of palliative care and then recommends that we "focus on a strategy with 3 levels: the state and national level, the institutional level, and the individual level." He concludes: "I hope we can feel secure in our seat at the table as we work to ensure that all people with serious illness and their families receive the standard of care: patient- and family-centered palliative care, based on their needs, and as early as possible."

**Diversity, Equity, Inclusion: Words Matter**

p. 16

*Christy Torkildson, PhD, RN, PHN, FPCN, HEC-C, Joseph C. Torkildson, MD, MBA, and Anthony Perillo, PhD*

"Words matter" is an important theme in our keynote article in this issue. Here the authors expand on that theme in a practical and insistent manner, especially as it relates to PPC. One important focus is how caregivers in our field document their patients, keeping always in mind "Who needs to know what when?" The article offers extensive resources and references to guide caregivers in these matters.

**Crowdsourcing Pediatric Palliative Care and Elevating the Pediatric Voice: The Story Behind The National Coalition for Hospice and Palliative Care's Pediatric Division (formerly The National Pediatric Palliative Care Task Force)**

p. 22

*Holly Davis, MS, APRN, Cheryl A. Thaxton, DNP, APRN, CPNP, FNP-BC, CHPPN, FPCN, ACUE, FAANP, Rachel Thienprayoon, MD, MSCS, FAAP, FAAHPM, and Devon Dabbs, BBA*

As its title indicates, this article traces the evolution of what is now the Pediatric Division of The National Coalition for Hospice and Palliative Care to become a formal body that can advocate on behalf of the field and increase access to services.

**A Children's Respite Home Is Where the Heart Is**

p. 24

*Kasey Kaler and Jonathan Cottor, MBA, MPH*

This article follows an earlier one by these authors in Issue #74 of our Pediatric e-Journal. Both articles argue for the critical value of respite care for children with medical complexity and for their family members. They offer several examples of both the need for respite in PPC and of responses to that need in particular cases and in a nationwide collaborative coalition. They conclude that, "A community-based children's respite home is an extension of a family's own home and a temporary haven." And they invite readers "to get involved and learn more about existing programs, emerging programs, or where talks of additional homes are happening" and "to join our mission to scale, strengthen, and sustain community-based children's respite, palliative, and hospice home programs."

**Prescribed Pediatric Extended Care**

p. 28

*Judy Zeringue, MAPL, BSN, RN, CPLC, CHPPN*

This article describes a Medicare benefit that provides "community based, family-centered, non-residential settings designed to provide compassionate, skilled medical care and therapies for medically fragile children who experience chronic health conditions." Children who meet the eligibility requirements may be covered from birth through 21 years old. The article provides examples from the states of Florida (PPEC-Prescribed Pediatric Extended Care) and Louisiana (PDHC-Pediatric Day Health Care).

**Pediatric Long-Term Care: A Place and a Role**

p. 30

*Matthew R. Misner, DO, MS, MAPS*

This article describes an important form of care and relief for families with children with complex medical conditions, namely pediatric long-term acute care (LTAC) facilities. The article describes both the benefits of such services and current barriers. It also gives examples of existing LTAC services.

**Toward a Definition of Adult Hospices Caring for Children**

p. 33

*Heather A. Davis, PhD, and Lisa C. Lindley, PhD, RN, FPCN, FAAN*

This article explores the guidance available for hospice services for children and young adults, identifies the differences between adult hospices and pediatric hospices, and proposes a definition of adult hospices that become involved in caring for children.

**State of Pediatric Palliative Care, Oklahoma**

p. 37

*Rachna May, MD, and Amanda Page, MD*

The authors of this article describe services offered by the sole program providing pediatric care in the state of Oklahoma. While this program serves approximately 400 patients annually, these authors note that, "Work remains to be done to capture all the children that would benefit from our services; we continue to strive to expand our services to fill this gap."

**Statewide Pediatric Palliative Care Coalitions**

p. 38

*Betsy Hawley, MA, and Christy Torkildson, PhD, RN, PHN, FPCN*

The authors of this article explain that "Statewide Pediatric Palliative Care Coalitions (SPPCCs) play a crucial role in ensuring that equitable palliative and end-of-life care is available in all areas of every state across the country." They explain that currently there are 29 states with some form of a SPPCC, including two regional coalitions, and they point out the key roles of such coalitions in collaboration and advocacy.

**Application of the Logic Model to Build a Statewide Pediatric Palliative Care Coalition**

p. 40

*Eileen R. O'Shea, DNP, APRN, PCNS-BC, CHPPN, Charlotte Delmonico, BSN, and Lisa McCabe, MSN, APRN, PCNS-BC, CCRN, NPJ-BC, NC-BC, CHPPN*

This article explains how a logic model "was used to establish a pediatric palliative care coalition in CT and create a work plan informed by a diverse group of stakeholders familiar with historical challenges and gaps in current resources in the state." It explains how stakeholders came together, obtained funding, established partnerships, and implemented short, medium, and long-term outcomes.

**ELNEC Palliative Care Education for Nurses**

p. 44

*Vanessa Battista DNP, MBA, CPNP-PC, CHPPN, FAAN, FPCN, and Betty Ferrell, PhD, CHPN, FAAN, FPCN*

The End-of-Life Nursing Education Consortium (ELNEC) curriculum is "a global education initiative to improve palliative care for nurses and other healthcare professionals." It was first launched in 2001, but by 2003 the need was clear for an ELNEC Pediatrics curriculum. This article describes that pediatric curriculum and explains how it is offered in an online format. The article also describes the launch in 2013 of the ELNEC Advanced Practice Registered Nursing (APRN) curriculum and in 2019 the initial offering of the ELNEC Graduate Curriculum for master's and Doctor of Nursing Practice (DNP) students.

**The Evolution of Child Life in Hospice and Palliative Care**

p. 47

*Jennifer Mangers-Deans, MHA, MS, CCLS, and Alyssa Friedberg, M.Ed., CCLS, GCCA-C*

The evolution of the role of Certified Child Life Specialists (CCLS) began in 2011 when "a hospice organization in Illinois hired a CCLS to create the first child life program for pediatric hospice and palliative care in Illinois. The goal was to provide emotional support, education, therapeutic play, sibling support, and legacy building focused on children diagnosed with a terminal illness and their families." By 2022, an online support group, "established to foster communication, collaboration, and camaraderie among CCLS in hospice & palliative care," had grown "to over 200 members working with children at the end of life." Subsequent developments are also noted in this article.

**Psychologists in Pediatric Palliative Care: The Future Is Bright**

p. 49

*Amanda L. Thompson, PhD*

This article seeks “to expand understanding of psychology’s role in PPC and how we contribute to research, clinical care, education/training, advocacy, and more.” The article identifies roles for psychologists in both assessment and intervention in PPC. Some initial points for consideration and guidance include different models of how psychologists can be integrated into the PPC IDT, how the need for such professionals can be assessed and data collected, and how business plans can demonstrate the holistic impact of psychologists’ inclusion.

**Spiritual Care Education to Support Pediatric Palliative Care**

p. 53

*Judy Zeringue, MAPL, BSN, RN, CPLC, CHPPN*

The author of this article points out that, “Spiritual care is an important aspect of total patient/family/caregiver care.” On that basis, she argues that, “Spiritual support is essential in providing holistic care and serving those entrusted to our care with respect and dignity” and provides some resources for professional growth in spiritual care.

**The Case for Enhanced, Proactive Professional Grief Care for Pediatric Hospice and Palliative Care Professionals**

p. 56

*Dianne Gray, B.S.*

This article argues that, “Bearing witness to the unique, profound suffering that accompanies children and their family members as they face acute pain and the emotional and spiritual suffering inherent in most pediatric serious illnesses, death, and grief journeys is beyond the scope of expertise for most hospice care providers.” On that basis, the author maintains that, “Providers of pediatric hospice and palliative care need a substantial increase in the scope and coverage under the employer-sponsored professional bereavement benefits that correlate to the length of time of service, role, and responsibility inherent in the provision of care of seriously-ill and dying children and their families.” This emphasis on what organizations can do in supporting staff can be one important aspect of a comprehensive program of personal and self-care in mitigating staff stress.

**Concurrent Care Payor Relationships: Development and Maintenance**

p. 59

*Allison Kuchar, MSCHA, MBA, CHPO, CEOLS, and Jessica Sturgeon, CLS, MT-BC, HPMT, NICU-MT*

This article offers a detailed discussion of some implications of the implementation of the concurrent care provisions of the Affordable Care Act whereby “children enrolled in Medicaid can have curative and/or life-prolonging treatment at the same time as hospice care.” The article focuses on relationships between hospice organizations and pay source stakeholders. Discussion is arranged under three main headings: Relationship Investment with Pay Source Stakeholders; Ongoing Concurrent Care Management and Collaboration; and Coordination of Concurrent Care. The article concludes: “Though the interpretation and utilization of concurrent hospice care can vary state-to-state, the establishment of relationships, expectations, and coordination remain a vital part of how hospice is offered to children nationally. The fundamental collaboration between agency and payor can set programs up for success and, hopefully, promote longevity in accessing end-of-life care for the pediatric population.”

**Items of Interest**

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# Introductory Message from the Pediatric Advisory Council Co-Chairs

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We are delighted to introduce this 75th issue of the NHPCO pediatric e-journal: ***A Celebration of the e-journal: State of Pediatric Palliative Care in the US***. Much has transpired within National Hospice and Palliative Care Organization (NHPCO) and its Pediatric Advisory Council since it published ***Issue 50: A Look Back and a Look Forward*** in 2018.

Formerly called the CHiPPS Leadership Advisory Council of the Children's Project on Palliative/Hospice Services, in 2020, we were re-named simply the Pediatric Advisory Council (PAC) of NHPCO. Although our name changed, our role within NHPCO has remained the same. Our goal continues to be to assist NHPCO in identifying, developing, and disseminating practical strategies to the community provider that advances care for children and their families coping with life-threatening conditions, with dying, and with bereavement.

**Advocacy.** In order to pursue this goal, PAC continues to advocate, at the local, state and national level, for resources for patients, their families, and their health care providers. The PAC has representation on each of the NHPCO Committees and Councils, called a pediatric liaison, to represent and give voice to the pediatric hospice and palliative care needs. The pediatric liaisons and committees are Tarek Zetoune (Quality & Standards), Christy Torkildson (Ethics), Steven Smith (Palliative Care) and Holly Davis (Regulatory). Holly Davis also serves as the NHPCO representative to the National Coalition for Hospice and Palliative Care (NCHPC) Pediatric Division, where she recently moved into the role as the Chair of the Division. The efforts of the pediatric liaisons help to integrate the pediatric needs into the work each Committee and Council at NHPCO does from finding financial and other resources, within the government and elsewhere, to adding quality of care for pediatric patients and their families. Currently, PAC is working on 2 projects focused on assessing how concurrent care is addressed within each state and working with private insurers for coverage of concurrent care. The newly updated Concurrent Care for Children Toolkit and the newly developed resource guide for working with private insurance will be made available in May 2024.

**Education.** In order to further pursue the goal of enhancing services received by the pediatric population, our mission is to help educate healthcare providers who may care for pediatric hospice and palliative care patients and their families in the community. Education of the community providers starts with assessing the needs of the field and access to quality pediatric palliative and hospice care. The Pediatric Standards of Care for Hospice Programs was updated and published in 2022. In May, PAC will be conducting the 2024 National Pediatric Needs Survey. The last Needs Assessment Survey was conducted pre-COVID, in 2020. Arising in part from information acquired by the previous Needs Survey and research, NHPCO published the Pediatric Facts and Figure Reports in 2023. PAC continues to offer regular education opportunities, through in-person and virtual conferences, webinars, as well as



publications such as resource guides and the e-journal that you are reading now. Guided by PAC members Christy Torkildson, Ann Fitzsimons, Betsy Hawley, and Melissa Hunt, this quarterly e-journal is the longest, continuous, peer-reviewed publication focused on pediatric hospice and palliative care in the US. These educational opportunities, spearheaded by the PAC, have been created to help address providers' needs for education/training, program development, and giving voice to the needs of our patients and families.

We wholeheartedly thank all the PAC members over these past 6 years who have selflessly volunteered additional time to serve on PAC and those who served as pediatric liaisons for other NHPCO committees or councils, in order to better represent the pediatric population's needs within NHPCO.

No summary of the past few years would be complete without mention of how the COVID pandemic affected us all. To the PAC and NHPCO members, COVID meant that our in-person annual meetings had to be inconveniently cancelled and changed to a virtual format. The COVID pandemic taught us how to successfully provide education via live virtual conferences, pre-recorded webinars, and saved video presentations. To the patients and their families, however, COVID represented one extra threat out there that could be the tipping point between life and death. To the health care providers, who might be pediatric palliative care providers, or who might be general pediatric providers or emergency room physicians not expecting to encounter so many critically sick infected patients, COVID shook us to the core. It made us feel our own mortality and to fear for our own health even as we cared for the sick people around us. The COVID pandemic prompted the fact that the topic of e-journal Issue #61 was **Self-Care of the PPC/Hospice Professional/Team**, that #62 was **Lessons Learned from COVID-19**, and Issue #63 was **Telehealth & Hospice/Palliative Care**. During the COVID pandemic, many health care professionals left the field, leaving a significant void that others tried to scramble to cover. Nevertheless, like the rest of the nation in other health care specialties, we are still experiencing shortages in staffing in the pediatric hospice and palliative care field. In hopes of developing more numbers of competent palliative care providers, there has been a move towards providing training and certification for midlevel career physicians partially on line.

As we consider the **State of Pediatric Palliative Care in the US** with Issue #75, we would like to "look forward" to our ranks being re-joined by people who have previously worked in the field as well as those who are new graduates, or who are hoping to expand their practice to become part of integrated pediatric palliative care teams. As the Pediatric Advisory Council of NHPCO, we look forward to advocating for appropriate staffing and reimbursement of providers, and look forward to continuing to provide excellent educational opportunities for pediatric palliative care professionals.

All of these resources mentioned above, as well as all of the previous issues of the E-journal, can be found on the NHPCO Pediatric webpage [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics). You can also email your pediatric hospice and palliative care questions related to program development, regulatory requirements and/or quality standards of care directly to NHPCO at [pediatrics@nhpc.org](mailto:pediatrics@nhpc.org).

In recognitions of all the hard work, dedication, and countless hours, we would like to extend our heartfelt appreciation and THANK YOU to each of the PAC members and E-Journal Workgroup members.

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# A Note of Thanks from NHPCO

**Ben Marcantonio**

COO and Interim CEO of NHPCO

I am excited to share the 75th issue of the Pediatric e-Journal and to celebrate members of the Pediatric Advisory Council and all other contributors who have made this esteemed publication possible for over twenty years!

The National Hospice and Palliative Care Organization (NHPCO) is proud to support the pediatric hospice and palliative care community through various resources, webinars, and the e-Journal. The Pediatric Advisory Council continually provides tools and support to both member and non-member providers as well as the patients and families they serve. Some of these resources include:

- Biennial Pediatric Palliative and Hospice Care Needs Assessment
- Pediatric Facts and Figures
- Concurrent Care Implementation Toolkit
- Private Insurance Concurrent Care Advocacy Toolkit
- Pediatric e-Journal Index

On behalf of the NHPCO team, thank you to members of the Pediatric e-Journal workgroup, the numerous journal contributors, and those who read and engage with this important content. Because of you—your time and resource commitment—we can continue to further our goal of ensuring high-quality, equitable, and accessible care for children living with serious illness. We look forward to countless more issues to come.

# A Newcomer's Perspective: What I Have Learned from Pediatric Palliative Care

**Michaila Kaufman, BSN, RN**

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As a registered nurse on the Pediatric Hematology/Oncology unit at Boston Children's Hospital (BCH), I had many positive interactions with the Pediatric Advanced Care Team (PACT), BCH's palliative care team. As I transitioned to join PACT as the Program Nurse, I tried to pinpoint, "What exactly makes palliative care so unique?" Evident on my first day, I found that pediatric palliative care (PPC) embodies a blend of clinical expertise and person-centered care, empowering patients and reducing suffering. I believe that this unique approach lies in the unparalleled skill set of our team members, who excel in the art of expert communication. Through effective and empathetic dialogue, we cultivate meaningful connections with patients and their families, fostering trust every step of the way.

I recall one of the first questions on my first new consultation: "Tell us about your child." It should have come as no surprise when the family began to respond with the intricacies of their child's medical journey, delving into diagnoses and the details of her medical history. However, I was surprised by our team's gentle redirection: "Thank you, but who is your child beyond her medical condition?" In that moment, I realized the most essential aspect of PPC is its unwavering dedication to knowing the individual beyond the illness, including their joys, fears, and aspirations.

In my previous role as a bedside nurse, discussions surrounding patient preferences were common but cursory. For the primary teams I worked with, patient preference was most often secondary to the intended course of action. Medical teams would decide the "best" course of action, most often based in science and prior experience, then present the plan to the patient and family. PPC flips this script by starting with the patient's preference, seeking to understand who they are, and practicing within those goals. While medicine has become exceptionally outcome-driven, which is incredibly important when seeking a cure, perhaps portions have lost sight of the care journey and what a patient experiences every day on the path to cure or recovery. Palliative care, and PPC teams in particular, can help re-focus our healthcare delivery on both positive outcomes and patient experience throughout treatment. In PPC, patient preferences are not merely considered but embraced as the guiding principle.

One of the most important lessons I have learned since joining the PACT team is the profound significance of effective communication, and that words carry weight. The language we choose isn't just semantics; it's a reflection of our respect for the individuality and dignity of each patient. Utilizing a mindful approach, we recognize that patients are not defined by their diagnoses, and their identities transcend any medical labels we may use. For example, we never describe a patient as "a DNR," but rather as "having a DNR order." Similarly, we refrain from reducing someone to a mere diagnosis, opting instead to acknowledge them as individuals "with osteosarcoma," rather than "an osteosarcoma patient." This subtle shift in language reaffirms the inherent worth and complexity of every person under our care.

Last month, I witnessed an interaction between one of our attendings and a patient's father that underscored the impact of clear and empathetic communication in the realm of pain management. The attending's ability to engage the father in a dialogue about his 5-year-old son's leg pain was remarkable. While the oncology team's

initial assessment attributed the pain to the severity of the disease, it became apparent that the current treatment regimen was falling short in alleviating the child's discomfort. What struck me most was the attending's ability to delve beyond surface observations and truly listen to the father's description of his son's pain. Through a prolonged and patient discussion, they unearthed crucial details: the pain wasn't just severe; it was tingling and radiating, indicative of nerve involvement. Armed with this nuanced understanding, we were able to tailor the treatment approach accordingly, initiating medication specifically targeting nerve pain. It was a testament to the power of effective communication in accurately assessing pain intensity and quality, paving the way for more targeted and impactful interventions.

Navigating the complexities of PPC often leads to profound moments of connection and understanding. It's a realm where decisions about treatment options, end-of-life care, and advance directives are delicately balanced against the backdrop of individual values and aspirations. In this intricate tapestry of care, I've come to appreciate the indispensable role of open and honest communication.

One of the most valuable tools for effective communication I have learned is the art of conducting family-team meetings to navigate difficult discussions. I've found that setting a clear goal for these conversations lays a solid foundation for meaningful dialogue. It allows for charting a course through uncharted waters, ensuring that everyone involved shares a common understanding. Central to the success of these discussions is the practice of active listening and validation. Our team utilizes the term "and" to emphasize the importance of acknowledging and affirming patients' experiences and worries, while also communicating providers' concerns. It's a subtle yet powerful tool that fosters a sense of understanding and validation, paving the way for collaborative decision-making.

I have also learned that, amid difficult discussions and complex decisions, there are moments when words fail to capture the depth of human experience. It's during these times that the simple act of presence becomes our most potent tool. For me, the art of "sitting in the space" with patients and their families, silently listening, can be really hard. Recently I sat on the bed with an intubated infant who likely would not survive the night, while my attending held his mother's hand as she cried and processed the news. Embracing "sitting in the space" requires recognition that healing doesn't always come in the form of treatments or interventions; sometimes, it emerges from the gentle reassurance of a compassionate presence.

Joining PPC nursing required a mentality shift. As a bedside nurse, I learned the art of efficiency and precision. The fast-paced environment demanded quick thinking and decisive action. The best days were ones that provided space to connect with patients for more than a few sentences. As a PPC nurse, I am encouraged to pause, allowing for meaningful conversations and genuine connections to blossom. Switching between these two worlds, I realized the power of balance. As a bedside nurse, I thrived in the urgency of the present moment, while as a PPC nurse, I find solace in the gentle rhythm of time. In a healthcare system driven by metrics and efficiency, the emphasis on listening and being present with patients can sometimes seem at odds with the push for streamlined processes and quick turnover. PPC's commitment to providing deeply personal and patient-centered care can be overshadowed by the demands for cost-effectiveness and productivity. I wonder, as PPC expands, how we can uphold these core principles of human connection and trust which takes time and patience.

My journey with palliative care has been profoundly enriching. I have found a deep resonance with its ethos, feeling embraced by its principles and values. As I continue to hone my skills in artful communication, I am committed to embodying the essence of PPC in every interaction. With boundless enthusiasm, I look forward to contributing to the advancement and growth of pediatric palliative care, ensuring that its transformative impact reaches every child and family in need.

# I'm Feeling Hopeful. I'm Feeling Anxious.

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Twenty-four years have passed since my daughter, Cameron, and nephew, Hayden, died from infantile Tay-Sachs. Our family's journey inspired the creation—with support from an amazing staff, expert contributions from families and clinicians, and generous donors—of a nonprofit organization, now in its 10th year, whose mission is to orient and empower parents and others caring for children with a serious medical condition. This organization, Courageous Parents Network, has worked with nearly 100 families and clinicians (thus far) to create and share tools and resources that educate and support all caregivers and to help inform important research. I have come to see myself as a journalist: my source is parents and clinicians, and my domain is the intersection of their lives and their experience. I come to the question of *How I am feeling about the future of pediatric palliative care and pediatric hospice care* with a sense of both humility and authority. That is, I come to whatever authority I have through intense and gratifying collaboration with others—what, as CPN's 10th anniversary comes around, we call This Shared Journey.

So how am I feeling about the future? More to the point, I think, is how I am feeling about the quality of care families will be receiving in the future. Well, I am feeling both hopeful and anxious.

The hope stems from three developments I have observed. First, the **field of pediatric palliative care** has grown from its pre-subspecialty birth to become an integrated program—sometimes as a unit, sometimes a department, sometimes a small team that is part of another unit—in most every major children's hospital in North America. I have been delighted to attend national academic conferences with tracks for pediatric palliative care and I have been privileged to sit at the table with pediatricians who are shaping the American Academy of Pediatrics' policy and technical and vision statements for palliative and hospice care. I have heard how non-palliative specialists (e.g., oncologists, cardiologists, neurologists) are increasingly referring families to their colleagues in palliative care so that they can better support the parents with anticipatory guidance, discussions of care goals, and medical decision-making.

Second, and this is what powers the First, I have spoken and worked at length with dozens and dozens of palliative-minded pediatric clinicians who dedicate themselves every day—whether as clinicians, as researchers, as thought-leaders and/or other agents of change—to the care of children with serious illness. Through this work, I have seen their incredible commitment to quality of life for the child, parental agency, and family well-being. They are curious. They have told me directly how much they value family voices and stories, to help them better understand the needs of the families they serve and to help educate their colleagues. And they are devoted: to children, to parents and siblings; and to making access to palliative care, or at least “palliative-aware” care, available for those who need it.

Third, I have seen in **parents** the growth in awareness and understanding of how palliative care can make a significant difference in how they shape the life of their child and family. For example, in the patient disease group with which I most closely identify, National Tay-Sachs and Allied Disease (NTSAD), families are now informed shortly after diagnosis about palliative care. Fewer parents confuse palliative care with hospice, leading the way to greater acceptance of palliative service. In fact, more parents are asking for it. More patient groups across diseases are asking Courageous Parents Network to present to their family members about the benefits of palliative care. And, more of the parents we speak with who already have palliative care as part of their child's treatment are themselves becoming champions for its inclusion. *Parents are spreading the word and other parents are listening.*

Why, then, the anxiety? It stems from two macro trends that are on a collision course in our country. I acknowledge that I am not an economist, an analyst, or a policy wizard. I know only what I hear and observe in the travels of Courageous Parents Network—and the message coming through is increasingly loud and clear.

Simply put, the systems in which we live and operate are not serving the children and families and the clinicians who personally bring passion and purpose to their care.

The first trend is the fact that remarkable advances in medical technology are allowing more and more medically fragile children to live longer and longer. Often, these children are living better too, but rarely are they living without complexities that place significant demands on hospital and community-based support systems and providers, schools, and, most importantly, on parents and siblings. And if they age out of pediatrics, into “adulthood,” these children are no longer eligible to receive most of the support services on which they and their families have come to rely.

As we know so well, the response to increase in demand for support requires a corresponding increase in money. However, our systems are not aligning to increase funding for the required supports. In fact, and this is the second trend, the systems are aligning in the opposite direction at every level: federal, state and private payer. Many hospitals, financially stressed by the long tail impact of COVID and the mandate to be more profitable, are reducing their numbers of pediatric beds and/or are asking more of clinicians. Hospital- and community-based palliative care teams are pressured to make the business case for their programs, with a misapplied insistence on quantitative measures or those honed in adult populations to do so. This pressure is even worse for for-profit hospices, and that number is likely to grow as private equity moves through the space. The Orwellian bureaucracy of billing codes, complicated by concurrent care, mires providers who just want to do the work. And the confounding inconsistency of Medicaid benefits across states, including the varying but consistently inadequate funding of waivers for families, further hamstrings and isolates families. These trends, along with other systemic factors, are contributing to clinician burnout and threaten increasing attrition.

And then there is the shortage of the home care nurses and personal care assistants who make it possible for families to care for these children at home. Inadequate compensation for home care providers has resulted in the paucity of care that has left parents and caregivers feeling more burdened and stranded than ever before. This is especially problematic for families reliant on nursing to keep those children dependent on mechanical ventilation safe at home. Everyone is at risk.

But ... to return to a hopeful note.

It is possible that our collective advocacy for patient-centered care and centering the voices of patients and families in research—to inform treatments and practice—will reveal truths that bean-counters cannot ignore. Likely, it will reveal the enormous downstream financial and societal costs of not supporting children and families where they live. Time will tell.

In the meantime, and perhaps most hopefully, we know that we are not alone. We must, always and in all ways, channel our devotion to children and families and our indignation at how our systems are failing both them and the clinicians who care for them, into finding our respective ways to insist on more, and better.

# Bereaved Parents as Educators of Clinicians: Reflections and Invitations for Continued Relational Learning Within Pediatric Palliative Care

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In under 25 years, the role of the bereaved parent advocate and educator has emerged and grown significantly within pediatric palliative care (PPC). With good intentions, many clinicians/researchers initially felt bereaved parents were too emotionally vulnerable and were concerned that participation could cause emotional harm. We have since found when parents (bereaved or presently caring for their child) engage in advocacy it becomes an opportunity for honoring their child in ways that are actively therapeutic. Parents' lived experiences provide essential wisdom that contributes to PPC maturation and healthcare as a whole.

One of the early catalysts that brought about this change was the Initiative for Pediatric Palliative Care (IPPC), established in 1998 as an initiative of the Education Development Center in Newton, MA. This national project opened doors for bereaved parents to be welcomed into core palliative care education as storytellers, advocates, educators of clinicians, and co-designers of care innovations. For example, IPPC modeled the vital importance of engaging bereaved parents as members of interdisciplinary palliative care teams and in clinician education.

The 75th anniversary edition of this journal provides a valuable moment to reflect on IPPC's innovations and to consider how this model continues to challenge and invite us all, parents and clinicians alike, to deepen the engagement of parents as educators as PPC continues to grow.

## IPPC's History

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Depending on when you entered the field of PPC, you may not have heard of IPPC (ip-see) or fully know of its work. Recently, I sought out Deborah Dokken, a bereaved parent who served as IPPC's Associate Director, for insights about the best practices developed through IPPC.

IPPC began as a research, quality improvement, and education effort to enhance family-centered care for families and children living with life-limiting illnesses and conditions.<sup>1,2</sup> Led by the Education Development Center, it included a consortium of seven academic pediatric hospitals across the US, the National Association of Children's Hospitals and Related Institutions (now called the Children's Hospital Association), the New York Academy of Medicine, the Society of Pediatric Nursing, and the Association of Medical School Pediatric Department Chairs.<sup>3</sup>

Initially, the IPPC project developed quality improvement tools and a 25-hour instructional curriculum, as well as an accompanying award-winning video series. Later, innovative educational regional retreats (2005-2010) for interprofessional teams interested in developing PPC skills proved to be groundbreaking for bringing parents to the forefront as educators of clinicians. Previous efforts to involve bereaved parents in educational settings were generally limited to a one-time parent panel or single session small group discussion.<sup>4-8</sup>



## IPPC's Innovative Retreat Design

The retreat design, through its "Families as Educators" component, consciously incorporated a significant number of family members, selected to participate as co-teachers and co-learners along with health care professionals. Family members were fully integrated as retreat participants; like clinicians, some also served in other roles including panel members, small group facilitators, and members of regional planning committees.<sup>9</sup> Feedback from the educational retreats, as well as data from an impact study done by IPPC, confirmed that the participation of family members not only enhanced the learning experience of clinicians but also contributed to institutional improvements.<sup>10</sup> Participation also maximized the learning of families themselves and helped them become more effective advocates and educators within their own communities. By January 2010, twenty-one retreats, involving almost 2,000 clinicians and over 300 family members, had been held across the US and in Canada.<sup>9</sup>

## IPPC's Foundational Beliefs

1. Bereaved family members and families of children with life-threatening conditions should be significant partners in education and change in the healthcare system.
2. Integrating family members fully in educational programs for healthcare professionals will improve care for children with life-threatening conditions and their families.<sup>9</sup>

IPPC's work was truly innovative. In collaboration with a significant consortium of stakeholders, the project had a large-scale impact on the field by significantly shifting the landscape of family/parent involvement in clinician education and program development.

## IPPC's Ripple Effect ~ a Brief Personal Reflection

In January 2010, while in the NICU, my son Levi received the gift of a palliative care consultation at two weeks of age. My husband and I were first time parents navigating Levi's severe HIE with medical complexities and hoping for a way to bring him home. Little did we know, our palliative care team from Children's Hospitals and Clinics of Minnesota were also serving as core faculty in IPPC's educational retreats, the last of which occurred later that same month. With palliative care support we learned to develop an in-home ICU, become Levi's advocates, and create joy in the midst of uncertainty. Keeping Levi's personhood front and center, transformed how we lived and made decisions.

## ~ Growing into Becoming an Advocate

Three years later while continuing to mother Levi, our palliative care nurse, Jody Chrastek offered me an invitation to step into advocacy.

*"Would you be willing to share a part of your story so other families could learn about palliative care?"*

Gradually, additional invitations were offered.

*"Would you join our state's pediatric palliative care coalition? We only meet quarterly."*

*"Would you be interested in co-teaching a pediatric ELNEC course on communication?"*

*"Would you consider writing an article for the Pediatric e-Journal?"*

Unbeknownst to me, the IPPC model of engaging parents was at work. With each invitation my communication and advocacy skills improved.

## ~ Growing into a Clinician Educator

Fast forward five years to when palliative care pediatrician, Naomi Goloff, invited another parent and me to become a part of the [Pediatric End-of-Life Skills](#) (PECS) workgroup as Bereaved Parent Faculty at the University of Minnesota's Department of Pediatrics. These half-day immersive simulation workshops teach high stakes EOL skills to pediatric subspecialty Fellows. As Faculty, our role grew as PECS grew, expanding parent involvement into full integration of this innovative trainee education: from inception to dissemination to further innovation of an interprofessional workshop. We provide a rare and brave space for trainees to be in dialogue with bereaved parents while developing EOL skills. Fellows consistently report increased self-efficacy as a result of these workshops.<sup>11</sup> This improves the quality of care families receive when their child is dying and it improves clinician competency and resiliency early in their career.

Now in its sixth year, PECS embodies and expands upon the IPPC model by:<sup>1</sup> integrating bereaved parent faculty into trainee education;<sup>2</sup> developing specialized training for onboarding new parent faculty; and<sup>3</sup> adapting trauma-informed care principles to meet the needs of bereaved parents.

## IPPC's Continuing Ripple Effect

A brief sampling of the spaces where bereaved parents are increasingly welcomed. Pause to remember the parents whom you have engaged with in these spaces and the embodied wisdom they shared.

- Pediatric e-Journal authors
- National convenings & task force
- Schwartz rounds
- Field-specific conferences
- State coalitions & advisory councils
- Legislative advocacy
- Ethics reviews
- Research co-investigators
- Provider-specific trainings
- Consultants

The emergence of [Courageous Parents Network](#) (CPN), founded by Blyth Lord, herself an IPPC parent retreat participant, is another example of how IPPC's work continues to grow. CPN leads magnificent work in increasing connections between parents and clinicians through gathering family stories, providing vital educational resources, partnering with research initiatives, and developing innovations like [NeuroJourney](#).

## Looking Ahead ~ Four Key Factors for Continued Growth

The IPPC model is essential for continued field development and deepening the role of parents, particularly in advocacy and clinician education. Relational learning is key to our future as clinicians and parent advocates grow symbiotically.

1. **Continue Learning from Lived Experience** ~ Opportunities to hear families' stories first hand provides essential insights. It is important for clinician work to align with the needs and experiences of families so we can identify when good care happens and where gaps and barriers remain, opening us to further innovation and systems change. A greater richness of insights will arise when stories are brought forward from multiple populations and diagnoses.

## Action Invitations

- Regularly identify and invite parents to share the stories of their lived experiences.
- Review the populations and diagnoses your PPC program serves and pursue the missing voices, including those with traumatic and negative experiences.
- Have a process in place to gather and share these stories (or partner with CPN).
- Integrate family stories into the forefront of your role in PPC.

- 2. Fully Integrate Parents into Education and Research** ~ IPPC retreats continue to be the standard bearer for parent involvement that reflects a fuller integration: beginning at ideation, through to dissemination and further innovations. IPPC's identified best practices still hold value and there remains a great need for the model of parents as key and equal members of PPC teams to be fully adopted across the field, particularly in education and research. In my role with the PECS workgroup, I have experienced firsthand how full integration improves trainee's outcomes while also growing parent's skills.

## Action Invitations

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- Review your educational curriculum and research initiatives. Do you have parents involved? If not, why not? Perhaps this relates to the first invitation of not yet having a process for bringing forward parent stories.
  - Review IPPC's best practice standards and the research resulting from the project's retreats.<sup>9,10</sup>
  - Begin involving parents earlier in the process, preferably at inception, as faculty/investigators instead of external consultants whom you occasionally reach out to. This is particularly important for research requiring community engagement and can be applied to national initiatives and conferences.
  - Create opportunities and allocate resources for deepening parent engagement and invite parents to co-create a transition process.
- 3. Address Sustainability** ~ The lack of sustainability is a major threat to retaining parent advocates who develop into clinician educators. By January 2010, 300+ parent educators had been involved in IPPC retreats. It is unknown how many of these parents are still involved in PPC. There are parents who can't come forward to share their stories or engage in longer projects because they don't have the capacity to take time off of work or be away from their children without financial compensation. We risk losing the benefits of accumulated wisdom and exhausting resources in repeatedly reinventing the wheel. Skills and effectiveness are gained over time through practice and repetition, including for new and seasoned parent advocates.

## Action Invitations

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- Build/expand peer to peer mentoring programs focused on parent advocacy skills. Wisdom sharing between established and newer members of parent advisory committees can be an important place to begin.
  - Offer in-person and virtual options for parent participation.
  - Maintain a roster of past, current, and possible parent advocates. Be in communication with them regularly about opportunities for engagement.
  - Include parent advocates in your research and educational budgets. It needs to become financially feasible for parent advocates to enter and remain in this work.
- 4. Develop Clear Educational Pathways for Parent Advocates** ~ One of the barriers to entry for a parent to become an advocate and develop into an educator of clinicians is the lack of a clear educational pathway within PPC. Few parents are offered comprehensive training in how to effectively tell their child's story. Sometimes this is found in diagnosis or cause-specific advocacy communities. Specialized planning and training are needed for parents to become navigators of their grief/trauma and effective educators of clinicians.

## Action Invitations

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- Offer storytelling training as an essential first step in developing parents as advocates. Explore what materials may already be available through your institution and through fields related to PPC.
- Engage current parent advocates in identifying the skills they have developed, skills they desire to develop, and resourcing available training opportunities.

- Lead/participate in a field assessment of available training materials for training parents as clinician educators. Identify gaps and collaborate in the development of missing materials.
- Explore how accessible education pathways in your institution/the field of PPC can be defined and developed for current and future parent advocates, related to specific clinician educational outcomes and field research objectives.

## Conclusion

IPPC provided our field with a valuable foundation through their core beliefs and innovative retreats for how to engage bereaved parents as integral and equal members of clinician educational experiences. This relational learning model impacted field development and continues to offer us continued guidance. In this anniversary moment it is important to celebrate the significant growth that has happened, since IPPC's last retreat in 2010, in incorporating parents into many aspects of PPC. Looking ahead, let's focus on providing bereaved parents with a clear educational pathway, sustainable resources, and opportunities for fuller integration into PPC clinician education and research. This will bring forth the diversity, embodied wisdom, and skillful parent communicators our field needs to foster meaningful maturation.

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# Palliative Care PR: Exploring New Message Strategies

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What do we talk about when we talk about palliative care? Well, most of us talk about some version of the Center to Advance Palliative Care (CAPC) definition: "Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially-trained team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient's prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment."<sup>1</sup> CAPC describes pediatric palliative care as, "It is appropriate for neonates, perinates, infants, children, adolescents, and young adults, and it can be provided along with treatment meant to cure." CAPC further specifies: "Pediatric palliative care is family-centered" and "Palliative care is based on need, not prognosis. It is best to start palliative care as early as possible."<sup>2</sup> And yet, despite the wonderful clarity of these definitions, study after study continue to show that around 70% of people don't know what palliative care is.<sup>3,4</sup> And despite the call to start palliative care as early as possible, referrals to subspecialty palliative care often come much later than we would like. Not only does it seem like this messaging has not been enough to break the palliative care stigma among healthcare workers, there is now even data that clinicians often project palliative care stigma onto patients and their families!<sup>5</sup> There also continue to be calls to rename our field<sup>6</sup> because "palliative care has an image problem." This may be somewhat of a self-fulfilling prophecy, as it often seems that those describing the image problem are also those same clinicians who stigmatize the image of palliative care in the first place. I satirically highlighted this dilemma in a YouTube video several years ago called "Palliative Care: We're the fire department, not the fire." [https://youtu.be/BbNi\\_-wYXJE?si=9MyPl6Hsbrfyzwx](https://youtu.be/BbNi_-wYXJE?si=9MyPl6Hsbrfyzwx)

So where do we go from here? Personally, I think it's time we stopped the dedicated focus on the minutiae of branding palliative care. I think we should stop engaging in conversations about whether we should change the name of our field. I think we should stop assuming we need to justify our seat at the table and just sit at the table. I'm mindful of the privilege I have to be able to reflect on this while practicing in the robustly developed field of pediatric palliative care. I'm keenly aware of the blood, sweat, and tears that so many who came before me have spent doing the groundbreaking work of building the field to where it is today. I know there was a role for tiptoeing in and asking to sit at the table, but I feel that time has passed. I reflect on the expression, "What you permit, you promote. What you allow, you encourage. What you condone, you own" and can't help but worry that we have a role in contributing to our diminution in the eyes of the medical community. After all, we are part of a field with a robust body of literature supporting its benefits. And while people may not know about it, when they learn what palliative care is they think it sounds fantastic!<sup>3,4</sup>

So rather than continuing to focus on our branding and worry about our image, what should we do instead? I believe we should focus on a strategy with 3 levels: the state and national level, the institutional level, and the individual level. On the state and national level, I think we should continue to advocate for policy related to palliative care and care for children with serious illness. Both policy to increase and standardize the provision of

primary palliative care to anyone with a serious illness as well as policy to increase the use of subspecialty palliative care and guidelines for involvement. Organizations like the National Hospice and Palliative Care Organization <https://www.nhpco.org/> do this every day on the national scale and the Coalition for Compassionate Care of California <https://coalitionccc.org/> is a wonderful state-level model. Additionally, guidelines like those provided by the Cystic Fibrosis Foundation provide a fantastic template for advocating for implementation of palliative care in an illness-specific model <https://www.cff.org/medical-professionals/models-palliative-care-delivery-individuals-cystic-fibrosis>.

On an institutional level, we could use the policies and guidelines above to enact standards of care and utilize institution-specific mechanisms to ensure palliative care principles are part of the care of all people with serious illness. While most institutions do not yet have robust enough palliative care teams to be involved in the direct care of every patient with a serious illness, having palliative care clinicians involved in standards of practice committees could be a start. Standards of care for both primary and subspecialty palliative care can be implemented and the committees can develop processes to ensure they are followed. We could define what constitute palliative care "never events" such as a patient dying with poorly controlled pain or other symptoms. We could also develop institution-wide educational initiatives to promote an upskilling of staff and leverage state and national guidelines to ensure these initiatives receive the time and resources they deserve.

On the individual level, this could take the form of reframes and pushbacks in communication about palliative care. Some years ago, I went to see a patient in the pediatric oncology clinic. An oncologist said to me, "I always enjoy seeing you, but it makes me sad to see you here, because it means someone is having a really bad day." I responded by saying, "You know, you work in a clinic for children with cancer, I suspect most people here might be having a bad day. I'm here to help someone have a better one." This reframe set the stage for further conversation about myths and stigma around palliative care that may contribute to a destigmatization of palliative care for this one clinician and benefit his future patients. Recently, my team and I were speaking to another medical team about a patient they were hoping we could meet, but they were worried about "sending the wrong message by consulting a palliative care team." We gently pushed back by sharing data that, in general, people aren't actually afraid of palliative care, they just don't know about it and when they learn about it are often interested in meeting a palliative care team.<sup>3,4</sup> We then kindly also shared data on how clinicians may inadvertently bias patients and families against palliative care in the way they discuss a consult.<sup>5</sup> The attending physician of that medical team responded with, "You're right! I've never thought about it before, but we do talk about palliative care consults with families differently than other consults." The robust conversation that followed was eye-opening for all involved and led to an invitation to present this discussion at the clinician's division meeting. Reframes and pushbacks shouldn't be antagonistic or adversarial, but they can still be firm. After all, what is the benefit of data if we don't use it to advocate for better care?

Ultimately, I hope palliative care clinicians can be proud to be in such an amazing field with a robust body of literature on its benefits. I hope we can feel secure in our seat at the table as we work to ensure that all people with serious illness and their families receive the standard of care: patient- and family-centered palliative care, based on their needs, and as early as possible.

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# Diversity, Equity, Inclusion: Words Matter

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When we first started planning the 75th edition of the Pediatric e-Journal (previously the ChiPPS Newsletter, ChiPPS e-Journal), we wanted to focus on the future and the issues we are still struggling with today. We wanted to look at all we have accomplished and what we still need to address. We wanted to celebrate and, at the same time, acknowledge the work that is still needed.

## Diversity, Equity, Inclusion

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Increased dialogue about Diversity, Equity, and Inclusion (DEI) principles has brought attention to the work needed to ensure equitable healthcare services to all, including those in pediatric palliative care.

We know that not all our children and families can access the services that can help support them.<sup>3,8,9,12,15,19,20</sup> We know that a significant number of our children with medically complex conditions are predominantly served by Medicaid and are challenged by social determinants of health.<sup>3,5,6,7,8,13,14,17,19,24,25</sup>

Recently (April 2024), the first author listened to a webinar on the intersection of behavioral health and the law directed by the co-author. The webinar addressed health professional roles in advancing equity for children involved in the legal system.<sup>21</sup> I again realized how much we can learn from many different disciplines and specialties. Although palliative care (and I used this term inclusive of hospice) has always been interdisciplinary, we have become somewhat exclusive in our thinking, prioritizing being and promoting ourselves as a specialty over focusing on the work itself and how we can work among and with various specialties toward a common service. Think about the discourses about the names of programs if you wonder what I mean. For a great perspective see Jared Rubinstein's article in this issue.

The Pediatric Advisory Council for the National Hospice and Palliative Care Organization (NHPCO) published the Pediatric Facts and Figures in 2023.<sup>24</sup> In this report, we noted the responses from the national survey of hospice and palliative care providers from 2019 to 2020 ([www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics)). We mapped where services were

available in the US based on our survey results (n=481). The Children's Hospice and Palliative Care Coalition of California completed an assessment of services in the state, creating an environmental map of pediatric palliative, hospice, and supportive services in California ([www.chpcc.org/resources](http://www.chpcc.org/resources)).<sup>11</sup> This map shows most services are clustered around the very urban areas of San Diego and Los Angeles, with few, if any, in other areas of the state, including the San Francisco/San Jose/Oakland area—home to over 9 million individuals and a significant number of children with complex medical conditions.<sup>10</sup> Additionally, Davis, et al (2024), examining adult hospice providers that cared for children in California, demonstrated a 30% decrease in hospices willing to care for children from 2018 through 2021.<sup>12</sup> This was consistent with concerning data from the NHPCO national survey.<sup>24,29</sup> An initial review of state data by the Children's Hospice and Palliative Care Coalition of California notes the same continuing trend with the most recent annual hospice and home care utilization report data from 2022.<sup>11</sup>

Work by Feudtner and colleagues has demonstrated that the large majority of children with complex medical conditions who could benefit from pediatric palliative care are predominantly served by Medicaid, and social determinants of health impacted a significant proportion of patients.<sup>6,8,13,14,17,19,25</sup> Due to the increasing population and significant needs of children with medical complexity, the American Academy of Pediatrics (AAP) updated its resources in 2022, creating a landing page on their website, "Children with Medical Complexity."<sup>3</sup> More recently, the National Institute of Health Eunice Kennedy Shriver National Institute of Child Health and Human Development convened a summit on "State of the Science of Pediatric Palliative Care" (Dec, 2023).<sup>26</sup> During the State of the Science Conference, we celebrated the rich history of pediatric palliative care while highlighting the ongoing need to further our work to provide equitable access to these critical services for children and their families. As Dr. Abby Rosenberg stated, we have "promise, challenges, and great opportunities."<sup>26</sup>

Work by Khaliah Johnson and her team in Atlanta highlights the significant impact of social determinants of health on health outcomes in pediatric healthcare including the effect of racism.<sup>19</sup> Levenson (2022) discussed trauma-informed care, noting that complex trauma is reinforced when situations are "chronic, multiple, and cumulative."<sup>18</sup> Levenson goes on to list factors that can lead to/cause trauma, including but not limited to loss, uncertainty, powerlessness, fear, adverse childhood experiences, illness, disability, historical and cultural trauma, stigma, discrimination action, and marginalization.<sup>18</sup> When we think of our patient population, many dealing with the impact of determinants of health, complex medical conditions, repeated hospitalizations, separations from family, pain, and, in many cases, suffering—physical, spiritual, and existential—it is not surprising that our families experience significant trauma.

I have always found it ironic that a child's rehospitalization is sometimes referred to as "normal." Although frequent hospitalizations for many of our patients are not uncommon, there is nothing normal about a child, any child, being hospitalized. This brings me back to my earlier statement about learning from other disciplines and fields. The April 2024 webinar referenced was presented by Jeanne McPhee, PhD, hosted by the University of New Mexico School of Medicine's Department of Psychiatry and Behavioral Sciences.<sup>21</sup> Her presentation was focused on forensic evaluations of youth, but her message emphasizes the need for "careful considerations of anti-blackness, trauma, and mitigating harm," from all involved in children's clinical services.

McPhee's talk highlighted some of the work led by Auguste, et al, (2023), who reported "recommendations for addressing harmful interplay..." of the American Psychology-Law Society's (APLS) Practice Committee, which stated in reference to forensic evaluations:

"consider how to be culturally sensitive in assessments, and acknowledge biases against black, indigenous, and people of color within risk assessments: Include information on race and ethnic backgrounds in the history or background sections... rather than simply including it in the first line of identifiers (e.g. name, age, gender, race, etc.)."<sup>4</sup>

McPhee, expanded on this message in her talk by recommending:

1. Do not attempt to remain "color blind."



2. Acknowledge being “color blind” or “race neutral” does not make us objective.
3. Aim to minimize racial bias in decisions by contextualizing decisions.
4. Be thoughtful and intentional in describing race and ethnic background.
5. Replace single line identifier with a section that contextualizes the culture and community (APLS Practice Committee, 2021).<sup>21</sup>

Riggs Romaine & Kavanaugh (2019) reported on the complexities of documenting race and ethnicity.<sup>28</sup> They wrote, “Always ask, sometimes write. Ask yourselves, will race/ethnicity identities provide context. Or will they be stereotyped and biased?”<sup>21,28</sup> These questions made me think about how we in healthcare start our notes. It has become rote to start with name, age, gender, race. We were taught to put as much information as possible into that first line; I remember my instructors saying, “Paint the picture.” But how are we thinking about race/ethnicity/sexual orientation when we are asking questions or about to write a note in the chart? What is the picture we are painting?

What are our preconceived notions when we read, “14-year-old black male with XYZ, living with single 30 y/o mom in subsidized housing.” What if we had written, “Arthur Green is a 14 y/o admitted via the emergency room with advanced diffuse intrinsic pontine glioma (DIPG) with a fever of 102 of unknown origin. Chest x-ray and ultrasound were completed in the emergency room, IV was placed with 18 gage angiocath in the right forearm, and the first dose of Rocephin was given IV at 1950. VS are XYZ, O2 Saturation is 92% on 2L/O2 via nasal cannula, the patient is alert and oriented X3 and denies any pain. Arthur identifies as a black male, a high school freshman, and an honor student. Arthur lives in subsidized housing with his mother and two siblings, one older and one younger. Social Work consult initiated.” There is so much more to everyone’s story beyond that one line, and that story can guide us to provide more equitable treatment.

What if the referral to hospice was written as, “Arthur Green is a 14 y/o black male with end-stage DIPG, living in subsidized housing with a single mother and two other siblings.” Or..., “Referral is for a 14-year-old male with end-stage diffuse intrinsic pontine glioma. Arthur is an honor student and freshman in high school. He attended school until this last hospitalization. Arthur has one older sibling and one younger sibling, all honor students. The family lives in subsidized housing with the mom, who is the head of the household.” Has a clearer, fairer picture been painted?

The American Academy of Hospice and Palliative Medicine’s Statement on Racism states, “Systemic racism undermines public health and poses a barrier to achieving our vision that all patients, families, and caregivers who need it will have access to high-quality hospice and palliative care.”<sup>1</sup> The National Palliative and Hospice Care Organization’s Code of Ethics calls for us to “provide quality hospice and palliative care services in a timely manner to all who qualify, regardless of race, religion, sexual orientation, ethnic background, or ability to pay”<sup>22</sup> and “to acknowledge, appreciate, and be sensitive to the unique needs of all patients and their families that we serve, inclusive of their background.”<sup>22</sup>

The April 2024 chat, “The Art of Documentation: What is Necessary and What is too Much When Telling a Patient’s Story,” by our social work colleagues at NHPKO noted since 2008 CMS has stressed, “the intent of the plan of care requirements are to show a direct link between the needs identified in the comprehensive assessment and the plan of care.”<sup>15</sup> Recommended guidelines included:

1. Focus on improving the quality of care for patients and families through an outcome-oriented approach to hospice care.
2. Describe a cycle of care in which assessment data about patient and family needs are incorporated into an individualized, patient-centered plan of care.
3. Gather assessment data in a systematic way that is retrievable to facilitate outcome measurements and quality improvements.

The panel of speakers went on to review when “Painting the Picture: What is Essential.”

1. The purpose of the encounter.
2. Who is present?

3. The focus of the encounter.
4. The patient/family's concern(s) during the encounter, prior to the encounter, and what is ongoing.
5. The patient's current functional status.
6. Any statements or behaviors that help to clarify the patient's status.
7. Any communication/care coordination needs.
8. Review of the planned intervention, including any referrals.
9. Any tools used to support assessments/goals/planned interventions.

Who needs to know what when? This should always be our guiding star, "Need to Know."<sup>15</sup> Not once during the hour-long chat did anyone state that it was essential to note the race or sexual orientation of the patient. This is not to say that race, sexual orientation, or other identifying information is never essential to understanding the children we treat. Rather, we should always consider what we are documenting and why. As noted above, provide the context, not just blanket statements that may lead to implicit biases—which we all have.

Goddu et al. (2019) found that stigmatizing language was associated with negative attitudes toward the patient/family.<sup>16</sup> Sun et al. (2022) found that black patients had 2.54 times the odds of having at least one negative descriptor in the history & physical notes such as agitated, non-compliant, combative, difficult, or refused.<sup>27</sup> These are just two examples, and although these studies were done on adult patients, we can extrapolate how this language can stigmatize if not pediatric patients, their family members.

As we strive to provide equitable, accessible, inclusive care to our patients and families, NHPCO's Code of Ethics also calls us to "acknowledge, appreciate, support, and remain sensitive to all staff and volunteers, with respect to all their identities and experiences."<sup>22</sup> We need to be as accepting of our staff and volunteers as we need to be of our patients and their families.

**The bottom line? Words do matter. Consider the picture you paint.**

## Additional resources may be found at:

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- Academy of Hospice and Palliative Medicine Diversity, Equity & Inclusion: <https://aahpm.org/membership/diversity>
- American Academy of Pediatrics issues their position paper AAP Diversity and Inclusion Statement "Words Matter: AAP Guidance on Inclusive, Anti-Biased Language: <https://www.aap.org/en/about-the-aap/american-academy-of-pediatrics-equity-and-inclusion-efforts/words-matter-aap-guidance-on-inclusive-anti-biased-language/>
- American Psychological Association Equity, Diversity, and Inclusion: <https://www.apa.org/about/apa/equity-diversity-inclusion>
- Hospice and Palliative Nurses Association Diversity, Equity, Inclusion, & Belonging: <https://www.advancingexpertcare.org/education-events/on-demand-education/22diversity-equity-inclusion-belonging/>
- National Association for Home Care & Hospice Diversity, Equity, & Inclusion: <https://nahc.org/archive/diversity-equity-inclusion/>
- National Association of Social Workers Diversity, Equity & Inclusion: <https://www.socialworkers.org/About/Diversity-Equity-and-Inclusion>
- National Hospice and Palliative Care Organization Diversity Tools & Resources: <https://www.nhpc.org/education/tools-and-resources/diversity/>

■ Pediatric Resources: <https://www.nhpco.org/pediatrics>

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# Crowdsourcing Pediatric Palliative Care and Elevating the Pediatric Voice: The Story Behind the National Coalition for Hospice and Palliative Care's Pediatric Division (Formerly The National Pediatric Palliative Care Task Force)

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*Crowdsourcing (def.) "an effort to solve problems, generate ideas, or complete tasks through collective intelligence and collaborative efforts."*

In 2019, a convening of national pediatric palliative care (PPC) leaders determined that a pediatric-specific national task force was critical to establishing alignment across the field and strengthening the field's capacity to deliver services. In response, with generous support from the Cameron and Hayden Lord Foundation, the [National Coalition for Hospice and Palliative Care](#) (NCPHC) launched a grant-funded initiative, the National Pediatric PPC Task Force, in the fall of 2020.

The Task Force's multi-disciplinary membership was comprised of diverse and emerging PPC leaders with representatives from [NCHPC's member organizations](#),<sup>1</sup> aligned stakeholder organizations including the American

Academy of Pediatrics, American Psychological Association, Association for Child Life Professionals, Network of State Coalitions, and family advocates.

Charged with identifying feasible action items to improve access to high-quality palliative care for children and adolescents, members "crowdsourced" and leveraged their collective expertise to advance relevant national PPC initiatives, legislation, and policies, and forge partnerships to develop educational and informational PPC resources.

NCHPC launched a concerted and successful effort to secure pediatric representation on national platforms focused on or aligned with palliative care including four NASEM (National Academies of Sciences, Engineering, and Medicine) workshops. Members actively worked to strengthen their representative organizations' commitment and understanding of pediatric palliative care, and pediatric representatives now sit on NCHPC's four standing workgroups—Advocacy, Communications, Equity & Inclusion, and Quality.

In December 2022, following the Dobbs vs Jackson ruling, the Task Force published a set of [PPC guiding principles](#) reconfirming its commitment to supporting all pediatric palliative care providers, children, and their families. This action was prompted by concerns voiced by PPC stakeholders, particularly perinatal palliative clinicians. Response to the guiding principles was powerful. Several PPC clinicians wrote to thank the Task Force for the "important" and "timely" communication while sharing firsthand experiences and observations on the impact the decision was having on individuals' autonomy to make their own healthcare decisions and their ability to practice evidence-based, compassionate medicine.

Last November, in recognition of the Task Force's proven value to the field, the NCHPC's Board of Directors unanimously voted in support of transitioning the Task Force to an organizational Pediatric Division.

Then Chair Rachel Thienprayoon, MD, summarized the impact of the transition, stating, *"For decades pediatric palliative care leaders have sought to establish a formal body, which can advocate on behalf of the field and increase access to services. We are exceedingly grateful to the National Coalition and its Board of Directors for supporting our efforts and for providing us with a home to continue this important work."*

The Task Force officially became a Division on January 1, 2024, and members from the Task Force now serve in the Pediatric Division.

The Pediatric Division remains focused on collaboratively advancing the field of pediatric palliative care by serving as or identifying subject matter experts, assessing needs, breaking down silos, forging partnerships, and advocating for critical change. Members recognize the need to be responsive and take the initiative on key issues, but the Division is not insular in its approach. It is broadening and strengthening its relationships with mission aligned organizations. It is also prompting and facilitating thought-provoking discussions about relevant and critical PPC topics including pediatric concurrent care and how it aligns and differs from adult concurrent care service, federal policy opportunities to create national consistency and access to PPC services, and the value and need to elevate the parent voice and engage families to promote equity, access, and quality. These conversations will continue to inform the Pediatric Division's advocacy actions going forward.

Members of the Pediatric Division continue to meet virtually each month to discuss key issues and initiatives and formulate strategies to address them. To stay informed about the Pediatric Division's activities and opportunities for participation and engagement, we encourage you to sign up for [NCHPC's Coalition Edition](#). If you have questions about the Pediatric Division and our work, please contact Devon Dabbs, director of NCHPC's Pediatric Division, at [devond@nationalcoalitionhpc.org](mailto:devond@nationalcoalitionhpc.org).

The Pediatric Division is chaired by Holly Davis, APRN. Rachel Thienprayoon, MD, serves as past chair and Melissa Hunt, PharmD is chair elect. The work of the Pediatric Division is generously funded by the Cameron and Hayden Lord Foundation and Y.C. Ho/Helen & Michael Chiang Foundation.

# A Children's Respite Home is Where the Heart is

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## A Glaring Gap in Services

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Caring for children with significant medical complexities is a demanding task that requires continuous and intensive care. This can leave parents and caregivers exhausted, with no place or person to turn to for rest or sleep. Relatives and friends who step up to help do not typically have the skills or training to provide the required care. While medical advancements have extended the lifespan of some children with life-limiting conditions, it also means that families are expected to provide much of the child's daily care for even longer periods.

Currently, an estimated one million children in the U.S. are living with very complex medical conditions, nearly one percent of all U.S. kids. Their intensive needs account for over a third of all children's healthcare spending and 40% of all child hospital deaths.

Being "medically fragile" and "sick" are distinctly different. The majority of a medically fragile child's life is spent living in the family's own home, not in a hospital or nursing home, which are utilized for periods of sickness. Cancer, muscular dystrophy, or thousands of "rare genetic diseases" typically have no cures, no treatments, and may dramatically shorten a child's life.

Families and caregivers are exhausted, stressed, and feeling lonely and isolated from a lack of support. Primary insurance eludes coverage, deferring to a state's Medicaid system for those who are enrolled. There is simply a severe lack of providers available to deliver care.

For Elli and her family, finding the right resources has been an arduous journey. Elli is a 22-month-old child with a brain abnormality who was living in New Jersey with her parents as her sole caregivers. Without support, they could not work, shuttling back and forth to appointments, leaving them only a few hours each week to run errands and rest.

Historically, the U.S. healthcare system has primarily focused on supporting aging adults and individuals with disabilities, leaving children's care mainly in the hands of parents. While major cities in the U.S. have welcomed the establishment of children's hospitals, which have become centers of excellence with specialists for children with complex medical conditions, a significant gap has emerged in dedicated children's respite services and resources for families when their child is living at home.

"This is such a niche field of pediatric, palliative, and respite care. We had to find the doctors comfortable enough even saying palliative to us. And that was just one hurdle." Elli's mom said. "When we did find a doctor in Jersey who was pediatric palliative trained, she couldn't even be our baby's doctor because she was heading the inpatient part of a children's hospital."

Elli's parents and the doctor worked hard to find creative solutions but ultimately fell into the system's cracks.

"Other than admitting her into the inpatient unit, there was no way to make respite happen for insurance purposes," mom said. "She would not qualify because she doesn't have a trach[eostomy] or a G-tube."

Those cracks in the system back many parents against the wall, expecting them to become full-time caregivers and stay breadwinners.

Elli's dad found a hint of help through their private insurance, providing several days and hours' worth of home health aides. But when his employer switched insurance plans, that support disappeared, and suddenly, mom needed more help than ever from dad.

"At that point, we had been doing that for about 20 months straight with very little sleep, and my husband ended up losing his job," Mom said. "So, we just didn't know where to go."

## Leading by Example

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In the early 2000s, dedicated pediatric respite, palliative, and hospice programs emerged in the U.S. These programs were inspired by successful care models established in the United Kingdom in the 1980s, starting with the world's first dedicated children's hospice home, Helen House, in Oxford, England. Efforts to improve the quality of life for children on life-limiting journeys had started even earlier, with some success in developing in-home services or ancillary programs in adult facilities. However, in the U.S., due to a lack of clear licensing and Medicaid reimbursement funding for pediatric care, launching dedicated pediatric "Homes" required relying solely on philanthropic strategies.

The first two dedicated pediatric "Homes" that emerged were George Mark Children's House in San Leandro, California, and Ryan House in Phoenix, Arizona. Each house was founded by passionate leaders who understood the glaring need for respite for parents and caregivers for children with significant medical complexities. The founding teams quickly learned the challenges of opening these programs within the current U.S. healthcare system. They relied on communicating the story of the real need for these homes, and private philanthropy. These founding programs became mentors, and along with other leaders who had begun pursuing care homes in their communities, came together as a coalition known as "Like Houses."

In 2018, Crescent Cove in Brooklyn Center, Minnesota, became the third dedicated pediatric "Home" inspired by the U.K. models to open its doors. Another variation, A Rosie Place for Children in South Bend, Indiana, focuses on providing overnight respite in a free-standing facility and has been actively sharing knowledge within the Like House Coalition since its opening in 2011.

The goals of these dedicated pediatric "Homes," are twofold. First, they aim to become an extension of a family's own home, providing essential support and care for children with life-limiting conditions and their whole families. Second, they serve as models for other communities seeking to establish similar initiatives. By sharing their knowledge and experiences, these programs collaborate to enhance the quality of life for children on life-limiting journeys.



## Forming a Collaborative Center

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By the summer of 2021, there was growing momentum to establish a national collaborative Center to share knowledge and address the challenges of opening pediatric care homes in communities across the country. Because no other national or state organization is positioned or prioritizing resources to address the need of provider growth at a local level, the National Center for Pediatric Palliative Care Homes (NCPCH) was established, welcoming community-based program leaders passionate about driving change to come together and share a common vision to grow the community-based provider network.

Children's Respite Homes of America (CRHA), <https://childrensrespitehomes.org/>, aims to raise awareness about the need for respite services for medically fragile children and their families. CRHA is the public face and fundraising arm of NCPCH. By creating a unified brand, CRHA amplifies the voices of grassroots programs and shares the stories of unmet needs in families.

The NCPCH organization, <https://www.ncppch.org/>, focuses on educating professionals about community-based respite and palliative and hospice care, aiming to create a collaborative national center for learning and addressing policy gaps. NCPCH champions practical needs to scale, strengthen, and sustain these important care models around business model optimization, licensing, and reimbursement methods. This is about closing the gap by building provider capacity.

NCPCH also collaborates with other like-minded associations, organizations, and coalitions that share a common purpose to enhance the quality of life for medically fragile children and families and improve healthcare delivery systems, recognizing that together, we're a powerful voice.

## A Mission to Scale, Strengthen, and Sustain

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Currently, there are 54 dedicated children's respite homes in the United Kingdom, compared to only a handful of known homes in the United States, despite the latter having nearly five times the population. To achieve the same level of family access to these critical care models would mean that someday, there will be at least 266 homes across the U.S. There is still so much work to be done!

Founders of new community providers can be anyone; what is common is a deep connection to this vulnerable population. Often, their dream struggles to take shape because they lack experience or knowledge on the business side of how to form an organization, become a nonprofit, develop effective boards, create strategic plans, and fundraising. They feel excited and relieved to discover they are not alone.

The overall goal is to develop the U.S. healthcare system to support these programs financially and operationally, ensuring their continued existence and impact in serving the needs of children with complex medical conditions and their families.

## Education and awareness are essential in this journey

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"Every story shared, every policy influenced, brings us closer to a world where our children's needs are understood and met," Jonathan Cottor, CEO and Founder of NCPCH, said. "The awareness raised is our voice, reaching out to those who can make our dream of accessible respite care a reality."

CRHA's awareness efforts have already begun to reach new passionate leaders who are connecting with NCPCH for inspiration and help to realize their dreams of opening a dedicated respite home in their community. Recently formed home programs in a number of U.S. cities, "Emerging Homes," can now leverage the expertise of NCPCH's

Government Affairs and National Advisory Councils to more clearly shape their own vision and business plans, which create a more aggressive timetable towards opening. CRHA's social media campaigns are working to reach more passionate leaders to expand this vital care network, including Elli's doctor in New Jersey, who has connected with NCPPCH to discover more ways to expand these services in her area.

CRHA's website, <https://childrensrespitehomes.org/>, maintains an up-to-date map of the existing and emerging conversations with new passionate leaders who are part of this national collective. This is an easy reference to find passionate leaders in cities nationwide. Encouraging others to become involved and creating forums of support are ways the community-based home provider network will expand to support more families.

## A Future Hope

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The need for dedicated children's respite services and support for medically fragile children and their families is clear. By taking action, a more inclusive and supportive healthcare system that meets the needs of all children, including those with significant medical complexities, can be a reality. Every new home that opens gives care access to 5,000 children and families.

"Early on, especially in our situation, my husband and I were allergic to the idea of hope. There's no hope for a cure or hope that she will live on and lead a typical life. So we didn't want that word involved. But now, I think our hopes are more modest. They are really to make sure that if you end up in a situation like ours, you're way more supported than we were," Elli's mom said. "We're sort of in the dark ages of caring for the families as a whole when they have medically complex kids. So that's kind of the hope, and it's like a future hope. And it's something we're just seeing scraps of right now. These things will happen, but hopefully, the country is more prepared."

A community-based children's respite home is an extension of a family's own home and a temporary haven. If you want to get involved and learn more about existing programs, emerging programs, or where talks of additional homes are happening, please visit <https://childrensrespitehomes.org/> or <https://www.ncppch.org/>.

We invite you to join our mission to scale, strengthen, and sustain community-based children's respite, palliative, and hospice home programs. Together, we can ensure that every family with a medically fragile child has access to the respite services they need and deserve.

# Prescribed Pediatric Extended Care

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"Prescribed Pediatric Extended Care (PPEC) can be a lifeline for families with children with special needs."<sup>1</sup> These programs are also called (PDHC) Pediatric Day Health Care. They are specialized care that offers support for medically complex children. Such children require skilled nursing and therapies to support their needs. This is a specialized Medicaid benefit, based on eligibility. The level of support varies by state as these programs have been established and continue to grow. The need for this support is significant.

PPEC or PDHC are community based, family-centered, non-residential settings designed to provide compassionate, skilled medical care and therapies for medically fragile children who experience chronic health conditions. Some of these children may be supported/dependent on medical technology to sustain their lives. These centers provide support for families through education and expert medical care to meet the individual child's special needs.<sup>1</sup> This Medicaid benefit allows for patients who experience complex medical conditions to receive medical care in a non-residential setting. Children who meet the eligibility requirements may be covered from birth through age 21 years old.

Services which are offered for care may include Nurses, Psychosocial Support, Childcare Therapist, Physical Therapy, Occupational Therapy, Speech Therapy, and Transportation. This nurturing environment offers compassionate care and therapies to support those with special needs.

NBC live, on January 19, 2024, ran an insightful story to provide a unique insight on "The Rise of Medical Daycares in the U.S."<sup>2</sup> It shares the perspective that these medical Daycares offer unique skills to meet the needs of children who experience complex medical issues and may be supported with medical technology.



<https://youtu.be/kfZncE-YvYk?si=L7X66qP9CCQfdyaZ/>

The NBC report highlighted the fact that only about 20 states have facilities in which a Medicaid funded program covers the cost of the day care. PPEC programs are most prominent in Florida and Texas. Based on the individual state, Louisiana has PDHC while Mississippi has PPEC.

Regardless of the model a state adopts, eligibility requirements remain consistent. To qualify for this benefit, a child must be medically dependent or technologically dependent. Their special needs are due to complex medical conditions and they require continual care.

Resources and respite are important contributions to these care models. Children who experience medical challenges may be cared for by skilled caregivers outside of the home. These children may receive therapies in this setting, and it provides a source of socialization. It also provides needed support for caregivers. An assurance that these medically fragile children are well cared for may allow a parent to have employment, care for family needs, and be a source of respite for a few hours. This support in communities allows support for those providing care for our most fragile and vulnerable children.

Guidelines for the State of Florida PPEC are provided as follows. <https://ahca.myflorida.com/medicaid/child-health-services/prescribed-pediatric-extended-care-ppec/>

"Prescribed Pediatric Extended Care (PPEC) centers allow Medicaid eligible children from birth through age 20 with medically-complex conditions to receive continual medical care in a non-residential setting. When approved, children can attend a PPEC up to a maximum of 12 hours per day while receiving nursing services, personal care, developmental therapies, and caregiver training."

Pediatric Day Health Care (PDHC) facilities and Prescribed Pediatric Extended Care (PPEC) are licensed by the specific State. As an example, according to the guidelines in the State of Louisiana, <https://ldh.la.gov/page/pediatric-day-health-care-facility#:~:text=%22Pediatric%20day%20health%20care%20facility,children%20who%20require%20close%20supervision/>

"Pediatric day health care facility" means a facility that may operate seven days a week, not to exceed twelve hours a day, to provide care for medically fragile children under the age of twenty-one, including technology dependent children who require close supervision."

The concurrent care Provision of the of the Affordable Care Act allows children with Medicaid coverage to receive disease-directed therapies while enrolled in hospice."<sup>3</sup> (p. 47) According to the NHPCO, "Concurrent care is for all children with a life-limiting diagnosis to continue to receive curative or life-prolonging treatment along with hospice care, avoiding the impossible choice between life-prolonging and hospice care."<sup>4</sup>

This concept is often misunderstood with those hospices who more often care for adult patients. Adults would not be eligible for curative treatment while simultaneously receiving hospice. Because of concurrent care, pediatric patients covered by Medicaid can receive support from hospice while enrolled in medical daycare or PPEC if they meet eligibility requirements.

Prior to the affordable care act, to enroll in hospice, which requires a prognosis of 6 months, one would give up the right to pursue medical treatment. For children, with the signing of the Affordable Care Act in 2010 for Concurrent Care, they may be eligible to pursue continued treatment and qualify for the support of hospice. Children who experience complex chronic conditions (CCC) can benefit significantly with the additional support of PPEC or pediatric medical day care. "Children with CCCs and their families live with the lifelong joys of having a child with special needs and also the challenge of life-threatening and life-limiting illness"<sup>3</sup> (p.466) As caregivers for these special children, PPEC or PDHC can provide an important support system to care for these children with expertise and can offer all the supportive therapies and socialization to help optimize their quality of life." In the United States, advances in pediatric healthcare continue to reduce childhood mortality while allowing children with complex illness to live longer."<sup>3</sup> (p.466) This additional support for the family can allow them to focus on sharing sacred time with their loved ones and providing the best care possible to enhance their quality of life.

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# Pediatric Long-Term Care: A Place and a Role

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The need to provide available care to children with medical complexity (CMC) is high. As more and more children require treatments that may involve multiple medications, as well as medical technology and equipment, parents now regularly face the difficult choice of placing their child in a long-term facility (Alon et al, 2022). Supporting the family's decision to care for their child at home is prudent, but the topic of pediatric long term acute care (LTAC) use deserves consideration.

LTACs are health facilities that usually admit complex patients as transfers from other acute care units such as ICUs. The reasons for admission might include the need for mechanical ventilator weaning, providing IV antibiotics, treating malnutrition, or addressing complex wound care (Munoz-Perez, 2009). Typical facility guidelines require that patients stay for a minimum of 25 days and then must adhere to any federal or state mandates that stand in order to assure the safety of those admitted.

Of course, pediatric patients are only part of the LTAC patient population. The number of adult patients needing LTAC intervention is increasing. An estimated one in seven older hospitalized patients will transfer to an LTAC facility as opposed to returning home (Makam et al, 2018). This accounts for over 130,000 stays and approximately \$5.3 billion in Medicare spending annually. Constructing more LTAC facilities helps to meet this need with a noted estimated 8.8% increase rate per year. To put this in perspective, there were only 192 available facilities in 1997 with a utilization of 38.1/100,000, yet this number increased to 408 in 2006 demonstrating an increased utilization rate of 99.7/100,000 (Khan, 2010).

The American Academy of Pediatrics (AAP) acknowledges a similar need for children. In the last decade alone, over 13% to 18% of children continue to exhibit some level of special need (Cohen, 2011). CMC represent a specific subset population who often require more intense treatment that often includes ventilatory support. Furthermore, the group represents diverse individuals who may exhibit congenital or acquired multisystem disease, those with neurologic conditions and associated functional impairment, or even pediatric cancer patients (2011, p. 529). As the number of these children increase, this simultaneously leads to a greater utilization of hospitals to meet the need. For instance, hospitalization rates for CMC increased significantly from 1991 to 2005 and continues today (Burns, 2010). However, unlike their adult counterparts, children do not necessarily have the option of transferring to a LTAC after their hospitalization terminates. Home care nursing (HCN) provides an alternative route for reentry purposes, but national shortages compound the situation (Maynard, 2019). Hospitals must then assume the responsibility to provide continual care and this in turn increases overall costs and discharge days (DD). One study notes this fact and demonstrates a worsening trend since 2001 (p. 6).

Furthering the difficulty of the situation, the need for LTAC assistance to children is unmeasurable. No definitive data exist to evaluate the number of facilities available or their locations (Alon et al, 2022). This in part is due to the fact that many of the children are receiving care within adult facilities as opposed to free-standing pediatric centers. Although facilities certified by Medicare and Medicaid are federally mandated to report a minimum set of data, this only applies to adult or geriatric patients. Any relevant information assigned to pediatric patients, such as treatments and issues related to their diagnoses, is not reportable (2022, p.1).

Other known barriers do exist and further hinder the pediatric LTAC discussion. Health care-associated infections (HAIs) periodically emerge and increase morbidity, hospitalizations, and mortality among children living in these facilities (Murray et al, 2015). Many of these infections are invariably passed through the use of medical devices, such as tracheostomies, that help the children needing them. Most of the infections are viral in nature including parainfluenza and influenza. Although following guidelines can help to alleviate transmission, one study notes the fact that staff members who leave the facilities will always serve as a potential reservoir for future outbreaks (2015, p. 758). Another valid concern for some parents and staff considering the option of placing a child on a LTAC unit is the risk for potential abuse. This may include the issue of patient neglect. The State Operations Manual defines neglect as the “failure of the facility, its employees, or service providers to provide goods and services to a resident that are necessary to avoid physical harm, pain, mental anguish, or emotional distress” (U.S. Federal Government). Although each individual state is mandated to document the use of bedrails and restraints, frequency of physician visits, medication use and distribution, and other protective information, it is often challenging to maintain secure environments for children, and this creates a chasm that parents are understandably reluctant or unable to bridge.

Despite the challenges that exist, a growing number of facilities do attempt to meet the needs of children by providing long-term care either permanently or during transitional periods. One such facility that deserves much credit for the care it provides to medically challenged children is the Ashley House in Spokane, Washington. It was created in 1989 to provide pediatric care to many who were either staying in hospitals for extended periods of time, resided in adult facilities, or were placed out of state for care (Dreher, 2021). The facility now serves many diverse children ranging from infancy to early adulthood. Protections are assured and full interaction rights of family and friends are maintained. Other organizations helping CMC include *Children's Healthcare Organization of Northern California (CHONC)*, *Ranken Jordan Pediatric Bridge Hospital* in St. Louis, *Blythedale Children's Hospital* in Winchester, NY, *Broward Children's Center* in Pompano Beach, FL, *St. Mary's Hospital for Children* in Bayside, NY, and *Harmony Street at ILIFF* in Dunn Loring, VA.

Another benefit of pediatric LTAC facilities is that they provide the opportunity for respite care when needed. This form of assistance relieves stressful and emergent situations for families who receive in-home services for CMC (Indiana Department of Child Services Child Welfare Manual, 2017). Families are allowed care for periods ranging from twenty-four hours up to 5 days at different intervals throughout the year.

In conclusion, advocating for the parental right to take care of their children at home is a sound decision. However, this may become a challenging feat with a medically complex child. Allowing parents the opportunity to seek alternatives outside of a PICU or adult LTAC facility makes good sense. Children deserve the security and comfort of being with their peers and parents need assurance that they've made the right decision to place. Advocating for pediatric LTAC use on both a state and federal level is prudent in that more and more children find themselves in need of this service. Although we as medical care givers may not cure CMC of their medical conditions, we can provide them with a more functional environment to advance and develop. Pediatric LTACs provide one avenue to make this a reality.

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# Toward A Definition Of Adult Hospices Caring For Children

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## Introduction

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Official definitions of adult hospices in the U.S. academic literature have proved difficult to identify. A search of the literature found several definitions of adult hospice care, but not of adult hospices caring for children. The Code of Federal Regulations (CFR) (C.F.R, 1983) and the Centers for Medicare and Medicaid Services (CMS) (Centers for Medicare and Medicaid Services, 2023) provide their own definitions of hospice which include private or public agencies and organizations that provide hospice care. Hospice care is further defined as care to those who are terminally ill and includes palliative and other supportive services during an individual's time at end-of-life. CMS's definition applies additional regulations to those who qualify for these services under Medicare and/or Medicaid. Additionally, states usually have a state-specific statutory definition of hospice facility which includes the necessity of licensure and certification to operate (Untitled California Assembly Bill No. 1847, 2014).

While it is assumed that those who qualify for hospice care under Medicare are adults, there is no specification as to what adult hospices and/or pediatric hospices are in the CFR's or the CFM's definitions. This is important because it vitally aids in understanding the service provisions available to children, who live in areas where pediatric hospice is geographically unavailable or otherwise not accessible. Therefore, we examined the differences between the provision provided by adult hospices who care for children and those provided by pediatric hospices in order to establish a definition for adult hospice and pediatric hospice.

## Criteria guidance for hospice provision to children and young adults (pediatric hospice)

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What hospices that provide care to children should offer to children and young adults at end-of-life is well documented in the literature (Vossel, 2023; Chambers et al., 2022; Shaw, et al., 2022; Johnston et al., 2017; Hospice Management Advisor, 2001). It is helpful to review the guidance laid out in the literature, so that a set of criteria may be developed by which to discern the differences between adult hospice and pediatric hospice.



This guidance includes:

- Inclusion of pediatric wings at hospice inpatient centers, which may or may not be facilities licensed under larger hospice organizations, and which are staffed 24 hours a day, 7 days a week, have sufficient administrative staff, and are accessible via transportation for children and their families
- Provision of comforting, calm, relaxing, welcoming, age-appropriate physical environments including (but not limited to) home-like rooms, appropriately sized furniture, furniture and spaces which allow family members to stay overnight with their child, outdoor spaces, and play spaces
- Undertaking of a risk adjustment of end-of-life care intensity measures because higher rates may be appropriate in pediatrics
- Provision of both respite and end-of-life care, and the range of staffing which is allowable under concurrent care may be shared between the respite and hospice pediatric patients; it is especially important that the hospice has a pediatric hospice medical director who is available twenty-four hours a day, seven days a week, and may make daily rounds if needed
- Provision of age-appropriate symptom assessment and treatment, support, clinical care, and services, i.e., a dedicated team of pediatric providers, who are clinically educated and certified to provide pediatric hospice care including full-time equivalent registered nurses, licensed practical nurses, certified nursing assistants, and child life specialists
- Provision of bereavement support and training for parents and siblings, creation of sibling assessment tools, surveys to assess bereaved parent outcomes
- Effective coordination with local children's hospitals, pharmacists with pediatric prescribing experience, and pediatric providers
- Support of patients and operational costs (if possible) through a variety of reimbursement and funding, including funding in addition to Medicare or Medicaid with consideration of between hospice programs/children's hospitals cost co-sharing partnerships

## Differences between adult hospices and pediatric hospices

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To establish a definition for adult hospices and pediatric hospices, it is helpful to examine how researchers and advocates (NHCPO, 2023; Shaw, et al., 2022; Johnston, et al., 2017; Hospice Management Advisor, 2001) have investigated differences between the two types of hospices and what their findings have been.

They identified:

- That adult hospices who care for children often have limited beds available for pediatric patients
- That the provider team assigned to pediatric patients had little training or experience in caring for children at end-of-life, and though patients may receive care from a pediatric hospice medical director, the remainder of their care came from the adult provider team
- That children often are admitted to hospice before a diagnosis is made, have a wider range of diseases/illnesses, die more slowly than adults, and have different admission criteria due to access to concurrent care, making adult hospice systems and procedures of care often inadequate for pediatric patients' circumstances
- That the family dynamic in hospice is different from that of adult hospice patients, with decision-making roles reversed between parent and child, and requiring the need for age-appropriate communication

Johnston and colleagues (2017) referenced the National Hospice and Palliative Care Organization's (NHPCO) 2015 Adult Hospices Facts & Figures stating, "While 78% of adult hospices that care for children, most only care for 1 to 20 patients annually and only 37% have formal pediatrics training" (p. e876). Additionally, the authors' stated that children and young adults spend much more time in hospice compared to adults (103 days versus 66 days) (p. 3875). In their most recent report on the state of pediatric hospices, NHCPO's needs assessment showed that less than 5 pediatric patients per day were the daily average service size of children while the average duration of stay was just under 147 days (NHCPO, 2023).

## Towards a Definition of Adult Hospices Caring for Children

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In the absence of an official definition of adult hospices caring for children, we recently published a paper defining adult hospices in California. For the purposes of that study, we defined adult hospices as hospices which treat less than five children per year, (Davis et al., 2023). The questions received by the pediatric hospice and palliative community prompted to us to re-examine the literature and provide a working definition that may encourage pediatric hospice providers, agencies, organizations, coalitions, and researchers to develop an official definition of adult hospices.

Edwards et al. (2021) provided a definition of adult hospices in the UK, which includes the groups who are covered in adult hospice provision (adults, life-limiting conditions, end-of-life), the types of organizations that operate adult hospices, the funding sources for those organizations, and the types of hospice services that are provided. This definition assisted us with our considerations. The criteria highlighted beginning on page one provide detailed information on what should be considered a pediatric hospice. Therefore, it may be considered, to a certain degree, that the lack of this same criteria aids us as well.

However, because some adult hospices do care for children in the US, the number of children adult hospices care for must be a primary factor. Here the NHCPO (2015) provides a helpful maximum number, twenty, which may be considered. There are additional ways adult hospices may support children, such as working with local children's hospitals and other health providers, organizations, and agencies to undertake the care of children, most often in the home. This may affect the understanding of or agreement on what defines adult hospice regarding the number of children served. With this in mind, and based on our clinical and research expertise, we have determined that the definition listed in our paper is the definition which we believe is best.

Therefore, we propose the following definition of adult hospices caring for children:

"A hospice provider who offers end-of-life support and services, either at home or in a facility primarily for adults and who cares for less than 5 seriously-ill infants, children, and young adults per year."

We believe that determining an accepted and agreed-upon definition of adult hospice will benefit children and their families, pediatric hospice and palliative care providers, administrators, researchers, and funders. For example, this may help the pediatric hospice and palliative care community in gaining resources and funding for training of adult hospice providers to care for children. Perhaps with more opportunities for this training, more adult hospices may undertake caring for pediatric patients with serious illness.

We encourage a dialogue about this definition within the community and advocate for its use.

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# State of Pediatric Palliative Care, Oklahoma

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The state of Oklahoma has one pediatric palliative medicine program, founded in 2015. At present, our pediatric palliative care team sees patients at Oklahoma Children's Hospital OU Health in Oklahoma City, the state's only pediatric tertiary care hospital. Our team consists of 3 physicians, 1 APRN, and 1 LCSW/bereavement coordinator. In addition to inpatient consults, the team also sees patients in the perinatal setting, runs a telehealth clinic, and provides palliative care services to a local pediatric subacute care facility. Our team partners with a local hospice agency to allow for patients to transition home at end of life should they desire. The hospital provides our team with excellent support services from psychology, child life, and chaplaincy.

For the past year, our team has been traveling around the state to provide palliative care education to pediatric health care providers, funded by a grant through Blue Cross/Blue Shield. To date, over 200 health care professionals have attended. Additionally, we host fourth year medical students, residents, and palliative care fellows on elective rotations with our team. In the last two years, we have sent 3 residents to palliative care fellowship.

In 2024, we moved to a continuous care model for our chronic, complex patients with higher order respiratory needs, such as tracheostomy and home ventilation. The complex care team, currently staffed by one physician and one respiratory therapist, is housed in the Section of Palliative Medicine. The complex care team works closely with patients and families to ensure a safe transition home. During this lengthy process, the team also focuses on development and quality of life, empowering patients and families to go on walks outside and attend story time in the sunlit hospital atrium. Patients transition back and forth between the palliative medicine and complex care team, depending on their present needs.

Between the two services, the Section of Palliative Medicine sees approximately 400 patients annually. Work remains to be done to capture all the children that would benefit from our services; we continue to strive to expand our services to fill this gap.

# Statewide Pediatric Palliative Care Coalitions

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Statewide Pediatric Palliative Care Coalitions (SPPCCs) play a crucial role in ensuring that equitable palliative and end-of-life care is available in all areas of every state across the country. While national initiatives help guide this newly emerging field, it is really on the state and local level that families needing pediatric hospice and palliative care for their children see the impact. And it is on a state level where community-based pediatric hospices and palliative care programs need support, resources, advocacy, and training.

SPPCCs are often a forum for emerging clinical leaders to learn how they can significantly impact health policy by addressing the needs in their state for their patients, their families, and providers. They provide a platform for networking that leads to resource and expertise sharing in organizations across a state. Coalitions ensure that the reach of end-of-life care for children can extend across an entire state, not just in the urban areas covered by tertiary medical centers. Collaborative efforts of SPPCCs have also creatively addressed needs that overlap geographic boundaries.

Presently, we have 29 states with some form of a SPPCC, including two regional coalitions—the Northwest Pediatric Palliative Care Coalition and the Gulf States PPC Consortium—which demonstrate remarkable collaboration across multiple states. Some states, like Vermont and Massachusetts, have government-staffed programs, while others are affiliated with established organizations, such as statewide hospice or serious illness coalitions. Moreover, 16 states have identified individuals as “PPC champions,” highlighting grassroots dedication to advancing pediatric palliative care.

In recent years, we have observed a surge in collaborative efforts among SPPCCs. Bi-monthly networking calls have become invaluable opportunities for information sharing, covering topics ranging from engagement with state foster care systems to navigating billing mechanisms for concurrent care. Formal collaborations have also emerged, such as PPCC of Pennsylvania serving as fiscal sponsors for three other SPPCCs (CA, OH, and CT) and exploring shared service models. The PPC Webinar Series, a SPPCC collaborative effort, continues to serve as a strong educational platform. <https://www.ppcwebinars.org/>

Advocacy remains a focal point, with SPPCCs actively lobbying for improved reimbursement models and raising awareness through advocacy days and partnerships with adult-focused groups. SPPCCs often focus on cultivating and maintaining relationships with state legislators, policy makers, and government officials so that they can react quickly to opportunities for input and action. Through collaboration and partnership with key stakeholders, SPPCCs have successfully spearheaded legislation and/or instituted federal waivers that authorize in-home PPC services in

Florida, California, Colorado, New York, Vermont, Massachusetts, Illinois, and Michigan. The charge to implement concurrent care for children under the Affordable Care Act has largely been led by SPPCCs. Other advocacy actions prompted and/or supported by SPPCCs include a school mandate to honor POLST (MI), extending the prognosis for hospice eligibility from 6 months to 1 year (MI), paid family leave for family caregivers (PA), an amendment of the state hospice provisions to protect and preserve pediatric concurrent care (LA), and extending concurrent care for young adults in hospice on their 21st birthday (CA).

Looking ahead, SPPCCs have a significant opportunity to amplify their impact through continued collaboration, partnership, and prioritizing the pediatric voice in advocacy efforts. By broadening their stakeholder base and sustaining collaborative initiatives, these coalitions are poised to drive substantial progress in pediatric palliative care nationwide.

Find up to date contact information for [SPPCC's and PPC Champions](#).

# Application of the Logic Model to Build A Statewide Pediatric Palliative Care Coalition

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Logic Models have long been beneficial for facilitating effective program planning, implementation, and evaluation (Kellogg Foundation, 2004). Typically, this tool provides a convenient way of mapping a program using two main components—the process side and the outcome side. The process segment outlines the program's inputs (resources), activities, and outputs (direct products), while the outcome segment delineates the anticipated impacts of the program, including short-term, intermediate, and long-term effects (CDC, 2017). Logic models may also incorporate underlying assumptions and contextual factors influencing the program or intervention (CDC, 2017).

When considering the development of a statewide pediatric palliative care coalition, a small group of passionate pediatric healthcare providers and leaders came together to brainstorm what it would take to develop a sustainable program. In this case, applying the logic model was a productive mechanism to strategize and initiate a map, linking activities and processes to future outcomes, program impact, and evaluation. The following describes one state's journey in developing a pediatric palliative care coalition.

## Case Study

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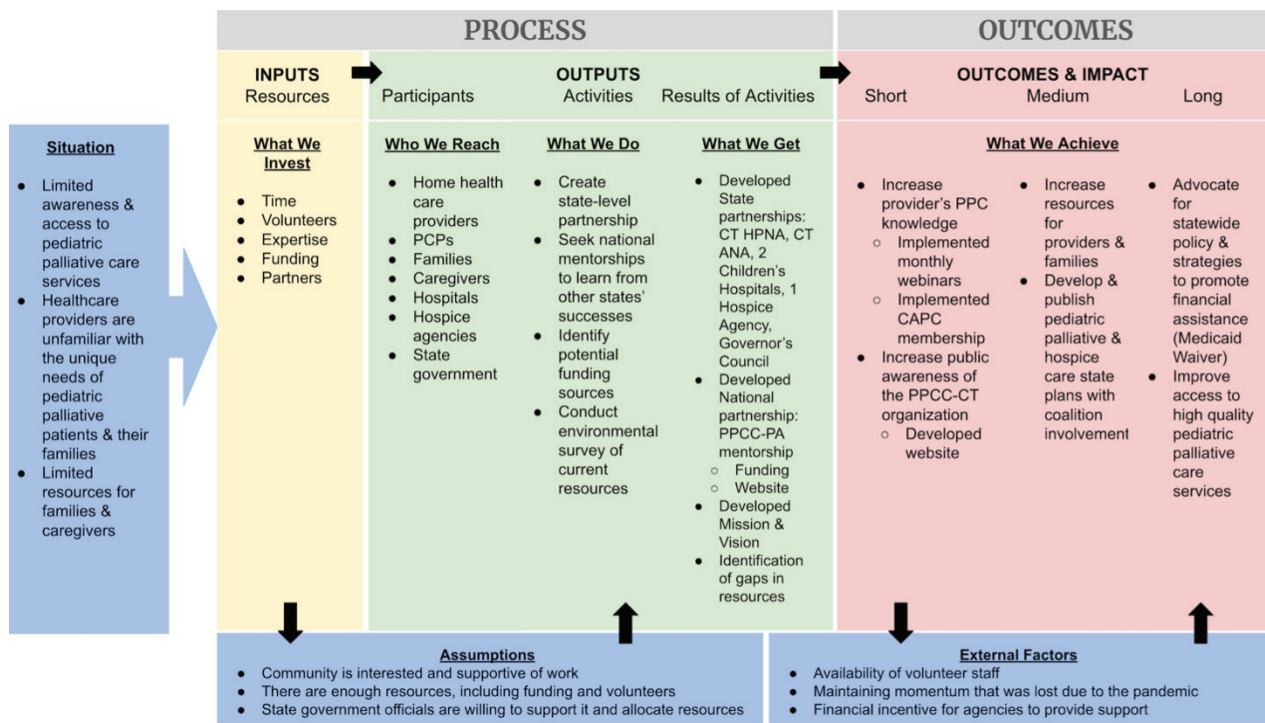
The American hospice movement was founded in 1974 in Branford, Connecticut (CT), with the establishment of Connecticut Hospice (NHPCO, 2024). Despite the significant strides made by adult hospice programs since the state's pioneering role in their development, pediatric hospice and palliative care have lagged behind.

Nearly 7,500 CT children live with complex medical conditions that limit their life expectancies and incur a substantial annual financial burden for families of \$82,000 per child (PedEOL, 2023). Additionally, CT has two nationally ranked children's hospitals, Yale New Haven Children's Hospital (YNHCH) and Connecticut Children's Medical Center (CCMC), equipped with pediatric palliative care programs. However, despite these acute care resources, critical gaps exist for children and their families when they transition care back to their homes. The sparse availability of community-based pediatric palliative care programs leaves families unequipped to navigate the complexities of caregiving. This lack of care continuity further contributes to their relentless emotional,

financial, and physical strains. It is imperative to address these gaps so that children and their families receive high-quality holistic care not limited by prognoses or care settings.

## Connecticut's Work Plan

Figure 1: Connecticut's Pediatric Palliative Care Map



## Process: Inputs, Activities, and Outputs

A logic model was used to establish a pediatric palliative care coalition in CT and create a work plan informed by a diverse group of stakeholders familiar with historical challenges and gaps in current resources in the state. The stakeholders included:

- Pediatric palliative care physicians
- Advanced practice nurses
- Registered nurses and one student nurse
- Hospice leaders
- Chaplain
- Bereaved parents

Virtual monthly meetings were held over a period of several months to accommodate participants from various locations. The discussions were primarily focused on identifying the present challenges (situation) facing community-based pediatric palliative care in CT. Historically, this field has been under-recognized and lacking adequate support, similar to other states. The stakeholders from CT have articulated the issues as multifaceted, encompassing limited public awareness, healthcare provider unfamiliarity, and the overall scarcity of resources, including financial support, for families and caregivers. The lack of public awareness regarding the existence of pediatric palliative patients has led to misconceptions and hindered the development of essential support structures.



Additionally, the CT stakeholders verbalized that while healthcare providers may be adept in adult palliative care, they often lack the specialized knowledge required to address the unique concerns of the pediatric patient population. Stakeholders concluded that there is a profound disconnect between the needs of these vulnerable patients and the resources available to them. Thus, these discussions led to the first three bullets of information in the CT Logic Model under “Situation” (See Figure 1).

Utilizing the systematic flowchart provided by a Logic Model template, stakeholders began to plan for the necessary inputs (resources) that would need to be invested to form a coalition. The highest priorities were to obtain funding and establish partnerships to learn about best practices, strategies, and activities to achieve results. Additionally, assumptions were made, such as the existence of an interested and supportive community that would be willing to volunteer their time and expertise.

Outputs, the tangible results of activities— or “what we get from our actions” (CDC, 2017)— documented our Coalition’s early progress. At the end of six months, our group had developed partnerships within our state, including the CT Nurses Association and the CT Chapter of Hospice and Palliative Nurses Association, and had received an invitation to meet with the Palliative Care Advisory Council within the CT Department of Public Health to report on our early achievements. Furthermore, this Coalition sought collaboration and mentorship with the Pediatric Palliative Care Coalition from Pennsylvania (PPCC-PA) from its inception. PPCC-PA is known as a national leader of palliative care state coalitions. Learning best practices and significant infrastructure support have rapidly launched this state coalition into operation of our work plan, with an eye on our short-, intermediate-, and long-term outcomes.

## Outcomes: Short, Medium, and Long-term

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From the foundation of defining who we are (mission) and what we hope to accomplish (vision), we move into the next phase of actualizing our goals and outcomes. Large group work is transitioning to committees that can focus on our short-term outcomes of increasing provider knowledge (i.e., education), public awareness/networking, and advocacy (i.e., medium and long-term outcomes [See Figure 1]).

Through our partnership with the PA coalition and a generous grant from the Kanarek Family Foundation, we have offered monthly educational webinars at no cost to participants. The webinars provide an opportunity to educate clinicians and raise awareness about pediatric palliative care. We are working to expand our invitation list to a broader community through collaborations with children’s hospitals, home care and hospice agencies, hospice and palliative care professional organizations, pediatric practices, parent groups, and academic settings. It is a slow process of making contacts and establishing relationships, often one at a time, as we bring awareness of our Coalition and the needs of children in our state to the greater community.

Concerning advocacy efforts, we recently provided written testimony for a raised bill requiring the Department of Public Health to create a plan to establish a hospice program for children in CT. We engaged our colleagues at the CT Nurses Association to guide us and look forward to ongoing collaborations. We are now tracking bills of interest to our Coalition within our state government. Once our advocacy committee is fully established, we will engage other stakeholders, such as the state Medicaid program, in mutual education and understanding of the needs of children and the payment system as they currently are. These necessary action steps (activities) align with the medium outcome to develop and publish pediatric palliative and hospice care state plans with Coalition involvement and both long-term goals (outcomes). Thus, the CT stakeholders can see how efforts are strategic in achieving our goals.

The creation of a website for our Coalition provides an excellent opportunity to increase public awareness of the work of our organization, as well as a chance to introduce the community to currently available resources. From this outreach, we aim to build enhanced relationships with community stakeholders and create a network for CT families to share and seek assistance. Further, community support will be essential to guide our Coalition in prioritizing our efforts and fundraising to sustain the work of the Coalition.

The key to our success will be maintaining an engaged and active community of individuals from various backgrounds, disciplines, and perspectives to inform and enhance our efforts. Through in-person retreats and networking activities, celebrations of success, and other interactive events, we hope to maintain interpersonal connections within the group to inspire, motivate, and retain our membership and collaborative partnerships well into the future.

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# ELNEC Palliative Care Education for Nurses

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## Introduction

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The recognition and acceptance of palliative care as a distinct specialty over the past few decades has aided both the expansion of services offered to individuals living with serious illness and their families, and the number of educational resources available to clinicians. Despite this growth, a demand for services still exists throughout the world, and seriously ill children remain the population most underserved in hospice and palliative care (Cormack et al., 2023). Also, the increase in the number of children living with serious illness globally, along with the increased complexity of their illness, suggests that pediatric palliative care services will continue to increase over time. This demand for increased palliative care services necessitates that all clinicians caring for seriously-ill children and their families be adequately prepared to deliver high quality pediatric palliative care and that palliative care education should be a part of clinical education across all specialties (Cormack et al., 2023). This is especially true for nurses, who are an integral part of the care that seriously-ill children and their families receive and spend more time with patients than any other health care professional (Battista & Sciacca, 2023).

In response to the need for nurses to have adequate training in providing palliative and hospice care, in 2000, the End-of-Life Nursing Education Consortium (ELNEC) curriculum ([www.aacnnursing.org/el nec](http://www.aacnnursing.org/el nec)) was created at City of Hope (Duarte, CA) in collaboration with the American Association of Colleges of Nursing (AACN) (Washington, DC) as a global education initiative to improve palliative care for nurses and other healthcare professionals (Cormack et al., 2023). The first ELNEC course was launched in 2001 and the project continues to provide training in palliative care for nursing students and practicing nurses, including undergraduate and graduate nursing faculty, continuing education providers, staff development educators, specialty nurses in pediatrics, oncology, critical care, geriatrics, and advanced practice nurses, as well as other clinicians (AACN, 2004). Since 2001, the program has grown tremendously and provided 301 courses in all 50 states, 114 countries, and education for 47,404 individuals as Trainers who in turn have educated over 1,528,471 individuals.

## ELNEC Pediatric Curriculum and Dissemination

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The ELNEC curriculum ([www.aacnnursing.org/elnec](http://www.aacnnursing.org/elnec)) began with a Core curriculum intended for nurses caring for adult patients and also included pediatric content. From the initial launch it was apparent that a Pediatric specific curriculum was needed and in 2003 ELNEC Pediatrics was launched. The curriculum follows the National Consensus Project (NCP)/Clinical Practice guidelines for palliative care with modules including Introduction to Pediatric Palliative Care, Pain Management, Symptom Management, Grief/Loss/Bereavement, Cultural Aspects of Care, Communication, Ethics and Care at the End of Life. The ELNEC Pediatric curriculum is updated annually and in recent years a module was added on Neonatal Care and Perinatal Care. This reflects the growing attention to palliative care in these pediatric settings. These modules address the unique aspects of Neonatal and Perinatal care including anticipatory grief, death rituals, as well as support for bereaved parents.

ELNEC Pediatrics is also offered in an online format through Relias ([www.reliasacademy.com](http://www.reliasacademy.com)). The online format is valuable for education in settings with limited ability for travel to in person conferences and is often used as a part of initial staff training. The ELNEC team hosts an in-person ELNEC-Pediatric "Train the Trainer" course each year and the Hospice and Palliative Nursing Association (HPNA) hosts an online ELNEC Pediatric course each year. The need for Pediatric palliative care training continues to grow due to many factors including the growth of Pediatric hospice and palliative care programs and the expansion of palliative care into more pediatric populations. As the benefits of palliative care to children, families and health systems continue to be well documented it will be important to continue to expand this education.

## ELNEC Advanced Practice Registered Nursing (APRN)

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In addition to the simultaneous need for increased palliative care services for seriously-ill individuals and education for nurses came the need for more specialized training in palliative care specifically for advanced practice registered nurses (APRNs). Numerous palliative care teams throughout the country are led by APRNs, which includes nurse practitioners (NP's), clinical nurse specialists (CNS), midwives, and certified registered nurse anesthetists (CRNA's) ([www.aacnnursing.org/elnec](http://www.aacnnursing.org/elnec)) who demonstrate leadership not only in the clinical arena but also as leaders in education, administration, and research (Battista and Sciacca, 2023). There are several factors that distinguish the role of the APRN from that of the registered nurse (RN), including educational preparation, scope of practice, ability to independently manage patients and in many instances prescribe medication, and, as such, APRNs working in the palliative and hospice setting also require distinct specialized training.

In 2013, more than a decade after the creation of the first ELNEC course, the first ELNEC APRN course, supported by Cambia Health Foundation, was launched in Anaheim, CA, with 115 APRNs, representing 26 states, in attendance ([www.aacnnursing.org/elnec](http://www.aacnnursing.org/elnec)). The APRN curriculum includes both an adult and pediatric track and course participants receive advanced education in topics as such as pain and symptom assessment and management and communication skills. Modules include Introduction to Palliative Nursing, Advanced Pain Management, Communication, Final Hours, Symptoms, Education/Teaching Strategies, as well as special topics such as Quality Improvement, Leadership, Well-Being, Financial Management, and Education ([www.aacnnursing.org/elnec](http://www.aacnnursing.org/elnec)). This curriculum is also updated annually and reflects the current needs of the expanding role of the palliative and hospice care APRN. Similar to the educational needs of the palliative and hospice RN, the need for pediatric specific APRN education continues to grow as the need for pediatric palliative care services increases and becomes more widespread.

Similar to ELNEC Pediatrics, the ELNEC Graduate Curriculum for master's and Doctor of Nursing Practice (DNP) students also became available in an online format through Relias ([www.reliasacademy.com](http://www.reliasacademy.com)) in 2019. This curriculum was specifically designed to meet the American Academy of Colleges of Nursing (AACN) G-CARES competencies for advanced practice primary palliative care and similar to the ELNEC Undergraduate/New Graduate online curriculum, contains six one-hour interactive modules with available content applicable to APRNs across all population areas ([www.reliasacademy.com](http://www.reliasacademy.com)). The modules include cases, videos including APRNs

demonstrating primary palliative care skills such as leading goals of care or advance care planning conversations, pain and symptom management, and leadership.

## International ELNEC – Pediatrics

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The need for Pediatric palliative care is an international priority with low resource countries being of special need. The wide range of childhood illnesses causing symptoms and quality of life concerns, high rates of mortality, and the incidence of serious pediatric illnesses such as HIV/AIDs, malaria, and infectious diseases create a demand for this care. The ELNEC curriculum has been used in 114 countries and most of these countries have included the Pediatric curriculum due to these needs in low resource countries. International clinicians have used the ELNEC Pediatric curriculum and adapted it to fit the drug availability in their countries and to reflect cultural considerations and the available workforce. Many international Pediatric courses have also included a large involvement of physicians who are also eager to advance pediatric care in these countries with such high needs.

## Summary

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The need for palliative care services for children living with serious illness and their families continues to increase and necessitates increased training and resources for nurses and APRN's working in palliative and hospice care. The need for Pediatric Palliative Care training will continue and is critical to insure a workforce for quality care. Pediatric Clinicians across all areas benefit from palliative care knowledge to integrate in their care and the ELNEC curriculum has served to meet this educational need for nurses and other healthcare professionals for over 23 years. Hospice and Palliative Care providers, as specialists in their field, will continue to develop this field and extend it to new pediatric populations and the expanding ELNEC curriculum will continue to enhance this growth by serving to meet the needs of nurses and APRN's providing high quality pediatric palliative care.

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# The Evolution of Child Life in Hospice & Palliative Care

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Certified Child Life Specialists (CCLS) serve as pillars of strength, providing invaluable emotional support and guidance to young patients and their families during times of uncertainty and distress. They offer a holistic approach to care, recognizing the innate resilience of children and the importance of addressing their emotional and developmental needs. Their goal is to minimize the stress and anxiety that children and families may experience. Historically, they have worked primarily in hospitals. However, the profession has evolved to meet the growing demand in various healthcare settings.

In 2011, a hospice organization in Illinois hired a CCLS to create the first child life program for pediatric hospice and palliative care in Illinois. The goal was to provide emotional support, education, therapeutic play, sibling support, and legacy building focused on children diagnosed with a terminal illness and their families. Identifying other professionals engaged in this work was challenging. Many were working in one-person programs. In 2013, an online group was established to foster communication, collaboration, and camaraderie among CCLS in hospice & palliative care. The aim was to diminish the sense of isolation experienced by many individuals and foster a community where resources, ideas, and care-related needs could be shared and discussed.

By 2022, that group had grown to over 200 members working with children at the end of life. Through this group, many areas of interest have been identified for research. A needs assessment was conducted of the community, with results that provided great insight into the field's current landscape. It showed that, as the need for child life services becomes more widely identified, CCLS have been finding new ways to deliver services to children and families. Many CCLS have branched out from the hospital setting and are now providing services to community-based organizations in full-time, part-time, consulting, and private practice capacities. This shift represents an exciting new trend in the field, that will ultimately benefit children and families, along with the organizations that choose to partner with CCLS.

The future for CCLS in the field of hospice and palliative care will benefit from ongoing research to ensure that the work continues to be evidenced-based and is rooted in the needs of children and families. CCLS need research and data to support their advocacy around implementing new programs and obtaining additional positions, all with the goal of being able to provide support to as many children as possible. It was found in the needs assessment that many CCLS in hospice and palliative care are concerned with burnout and staffing, so having data to support the

need for additional CCLS is key. There is also a need for research around DEI in the field, as the most recent needs assessment identified a widely homogenous field. Future research in this area will help push the profession of child life forward, making services more accessible to families who need them most.

It is an exciting time of change and progress in the field of child life, especially within hospice and palliative care. There's ample opportunity for growth, which will continue to benefit both organizations and families.

# Psychologists in Pediatric Palliative Care: The Future is Bright

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Pediatric palliative care (PPC) is an interdisciplinary profession by definition, and a culture of collaboration is foundational to how we care for patients and families. For some time, social workers and chaplains have been recognized (rightfully so) as core and essential members of the PPC team;<sup>1</sup> psychologists, however, have not yet been consistently integrated into PPC practices.<sup>2,3</sup> Further, pediatric psychologists, despite their extensive training and expertise in the care of young patients with serious medical conditions, have been underrepresented in PPC clinical models, national guidelines, and training programs.<sup>1,2</sup> A group of passionate and dedicated providers have been working to change this narrative, to expand understanding of psychology's role in PPC and how we contribute to research, clinical care, education/training, advocacy, and more.

First things first: "pediatric psychology," a subspecialty of both child clinical psychology and health psychology, is the interdisciplinary field of research and practice that addresses physical, behavioral, and emotional development as it interacts with health and illness in children, adolescents, and families. Pediatric psychologists have expertise in child development, family system approaches, behavioral interventions, and the interaction between psychological factors and physical health in children and families. This training and expertise allows us to distinguish between normative adaptation to illness and clinical symptoms that may benefit from intervention. We do so through evidence-based biopsychosocial assessment of mental and behavioral health conditions, evaluating the developmental, physical, emotional, social, environmental, cultural, spiritual, and family systems factors contributing to patient presentation.<sup>4</sup> Pediatric psychologists are adept at selecting and tailoring instruments that are suitable for busy medical settings, considering cost effectiveness, time efficiency, and ease of use,<sup>5</sup> as well as mitigating confounding variables inherent to disease and medical treatment processes. Interventions delivered by pediatric psychologists are evidence-based and focused on alleviating emotional and physical suffering. Notably, pediatric psychologists excel in addressing some of the most prevalent and distressing symptoms reported by children with serious illness including pain,<sup>6,7</sup> sleep/fatigue,<sup>8</sup> and anxiety/fear.<sup>9</sup>

Despite the training and skills that position pediatric psychologists as integral to the care of youth with serious medical illness, less than one-quarter of PPC programs in the United States have psychology representation within the interdisciplinary team (IDT), with psychology only formally integrated into 17% of those programs.<sup>10</sup> Instead, over three quarters of psychologists engaged in PPC work are members of medical subspecialty teams with patient populations that frequently utilize PPC services (e.g., hematology/oncology, cardiology, NICU; 10). Identified barriers to psychology integration into PPC include lack of funding, overlapping roles with other psychosocial providers, absence of institutional/departmental support, and limited understanding of and/or recognition about the services psychologists can provide to enhance the care provided by interdisciplinary PPC teams.<sup>10</sup>

Therefore, in order to define the role and unique skillset of psychologists practicing in PPC, support psychology's systematic inclusion as part of PPC teams, and standardize best practices among the PPC psychology workforce, a working group of nine pediatric psychologists developed core competencies for psychologists practicing in PPC.<sup>11</sup> These



competencies, published in 2023, underwent extensive interdisciplinary review by a diverse group of PPC professionals and parent advocates and covered cluster areas of Science, Application, Education, Interpersonal, Professionalism, and Systems. Each cluster includes essential competencies (i.e., knowledge, skills, attitudes, roles) and related behavioral anchors (i.e., examples of concrete application), thereby highlighting psychology's unique contributions to and value in PPC. A full table of the competencies are available in the supplemental materials of the original publication,<sup>11</sup> but a small, amended excerpt from the "Application" cluster is provided below by way of example:

**Psychology Competencies for Pediatric Palliative Care-Application Cluster (excerpt, amended)**

Domain	Essential Competency	Behavioral Anchors
Assessment	Assesses suffering (physical and existential) caused by common symptoms associated with serious illness, including depression, anxiety, pain, nausea/vomiting, constipation, fatigue, dyspnea, delirium, and agitation	<ul style="list-style-type: none"> <li>■ Integrates behavioral observations, caregiver report, patient report, and known medical factors to conceptualize patients' symptom presentations</li> <li>■ Critically evaluates appropriateness of existing psychosocial instruments within the context of confounding factors (e.g., physical symptoms directly resulting from medical diagnosis, biological aspects of the dying process)</li> <li>■ Assesses for delirium in seriously ill patients, accurately differentiating symptoms that mirror emotional/adjustment-related presentations (e.g., agitation, spontaneous tearfulness)</li> </ul>
	Assesses the biopsychosocial, developmental, environmental, spiritual, and family systems factors that can impact children with serious illnesses	<ul style="list-style-type: none"> <li>■ Identifies how culture, self-identification of racial group and gender, sexual orientation, religion and spirituality, context (e.g., social drivers of health, systemic racism/inequitable systems), and the intersectionality of these constructs may influence patient and family communication and decision-making in the context of a serious illness</li> <li>■ Contextualizes patients' presentations within knowledge of known cognitive and developmental differences observed in certain PPC populations</li> <li>■ Assesses patients' understanding of their medical diagnosis, treatment, and prognosis relative to their developmental level</li> <li>■ Evaluates gross cognitive capabilities to screen for impairment and refers for comprehensive neuropsychological/developmental testing if indicated</li> </ul>
Intervention	Implements evidence-based biopsychosocial interventions focused on improving quality of life and supporting patients and families' coping throughout the youth's illness trajectory	<ul style="list-style-type: none"> <li>■ Teaches non-pharmacological strategies for symptom management (e.g., nausea, pain, fatigue, dyspnea) and relief including diaphragmatic breathing, hypnosis, imagery, and biofeedback-assisted relaxation training</li> <li>■ Utilizes evidence-based therapy approaches with patients and caregivers, such as cognitive-behavioral therapy, acceptance-commitment therapy, motivational interviewing, meaning-making, and dignity therapy to address anxiety, depression, medical traumatic stress, existential distress, etc.</li> </ul>

In making competencies explicit, we join our colleagues in other disciplines who have defined their roles within PPC and hope to promote better understanding among other healthcare professionals and within healthcare systems of the contributions of PPC psychologists and how our unique skillsets in empirically based assessment, intervention, and research add value to the IDT.

Building off the momentum from the competency development, a subset of the Competencies Working Group authors published a companion paper in the *Journal of Pain and Symptom Management* earlier this year to make the case to our medical colleagues for psychologists as critical members of PPC teams.<sup>12</sup> We highlighted evidence that:

1. Children with serious medical illnesses are at increased risk for the development of mental and physical health symptoms, including depression, anxiety, pain, nausea/emesis, fatigue, delirium, and dyspnea,<sup>13,14</sup> and that psychosocial distress is associated with decreased quality of life;<sup>15</sup>
2. Symptoms respond to psychological treatments and intervention. That is, psychology involvement for youth with serious medical illness reduces the distress associated with depression, anxiety, and other mental health concerns; decreases suffering related to physical symptoms; prevents or mitigates the exacerbation of illness; and promotes adherence to treatment regimens;<sup>16</sup> and
3. Psychology involvement saves money by decreasing hospital lengths of stay and overall hospital costs.<sup>17</sup>

We also discuss pediatric psychologists' expertise in research design and implementation and contributions to team education, dynamics, and well-being.

Slowly but surely, we are starting to see a shift toward increasing recognition of mental healthcare as a core feature within palliative care overall and pediatric palliative care specifically, and with that shift, a need for psychology support on IDT teams. In the past year alone, we have seen an increase in PPC programs hiring psychologists onto their teams. We hope to see this trend continue, and encourage institutional leaders (i.e., chiefs, program directors) to utilize the PPC psychology competencies to create nuanced and thorough job descriptions and to assess potential candidates' knowledge, skills, and attitudes. We have also worked to have an increased presence of psychology at national conferences and on national committees, work groups, and task forces so that we have a voice and literal "seat at the table" alongside our medical and psychosocial colleagues who are defining the future of pediatric palliative care, research, and education. For example, pediatric psychologists are now represented on the Pediatrics Council of the American Academy of Hospice and Palliative Medicine and the Pediatrics Division of the National Coalition for Hospice and Palliative Care, are active members of the Pediatric Palliative Care Research Network and the Network of Pediatric Palliative Care Educators, and are Sojourns Scholar Leadership Program Award recipients—this was not the case a mere 5 years ago.

As the tides are beginning to turn, we are excited about opportunities for psychology's role in PPC moving forward. We still have work to do, but we are committed to increased integration of psychologists as members of the IDT and view this as an important direction for the future of the field. Together, we have the opportunity to broaden and deepen the scope of services provided by PPC teams and to improve the experience of and outcomes for children with serious medical illnesses and their families.

If you are considering integrating a psychologist into your IDT, we provide you with some initial points of consideration and guidance:<sup>12</sup>

- **Model of Integration:** There are several options to consider when looking to incorporate psychology services within PPC. In a consultative model, psychologists working in medical subspecialties (e.g., oncology, cardiology, NICU) can offer external expertise to the palliative care team through ad-hoc clinical consultations. An embedded model, in contrast, involves psychologists being formally integrated within the palliative care service as a core member of the team. Each model has different implications for interdisciplinary collaboration, hospital resource allocation, acceptance and timing of services, and more. The consultative model, although widely adopted in pediatric hospitals, may create barriers to collaboration among consulting services (e.g., potential communication gaps, limited integration contributing to more fragmented patient care, limited interdisciplinary understanding).<sup>18</sup>
- **Needs Assessment and Data Collection:** Data on specific psychological support needs within hospital departments/units along with a cost-effectiveness analysis should be compiled. Consider including patient volumes, payor mixes, psychology per-patient reimbursement potential, and unique value added of psychology in relation to other possible service options.

- **Business Plan:** Developing a detailed business plan outlining roles, responsibilities, and outcomes is crucial, as is addressing concerns about staffing and budget constraints. Interdisciplinary collaboration benefits (supported by patient testimonials) can demonstrate the holistic impact of psychologists' inclusion. Addressing concerns about long-term sustainability ensures a well-rounded proposal.

We welcome ongoing partnerships with our interdisciplinary team members in the field and have extraordinary gratitude for those who have and continue to champion inclusion of psychology services for children with serious illness and their families. Our future is stronger together!

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# Spiritual Care Education to Support Pediatric Palliative Care

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Spiritual care is an important aspect of total patient/family/caregiver care. "It is as important for health care professionals to talk with patients (family/caregiver) as it is to address the physical aspects of care."<sup>1</sup> It is important to consider the difference between Spirituality and Religion. Spirituality is a much broader concept. It may be thought of as a person's search for meaning in their lives and purpose. These people may find strength and hope in relationships or nature, to name just a few. Religion may or may not be a component based on the individuals' beliefs and that which brings meaning or purpose to their life.

Spiritual care is about being honest, sincere, and authentic, thereby permitting our compassionate humanity to impact another in need. "Religion is one way, one very important and significant way, that we express our spirituality."<sup>2</sup> Spirituality may be expressed in different ways. Perhaps the beauty of nature, the joy of hearing a child's laughter, the gentle touch of shaking hands or offering a hug, praying or sitting attentively in silence with one experiencing grief. All are unique means of experiencing our unique spirituality. "Beyond religion, with all that it offers some people, there is the broad sense of spirituality or faith that is an outgrowth of one's beliefs about life."<sup>3</sup>

There are many religions in the world. Each brings their unique beliefs, rituals, and practices to consider with impending death and after death. These beliefs may impact health care decisions as well as considerations at time of death and bereavement practices. An understanding and openness to learn with cultural humility is what is important to support a patient/family/caregivers' beliefs, meeting them where they are and supporting them throughout their journey. If they desire a specific ritual or sacrament, we may offer to facilitate contact with their specific faith leader through our Chaplain. Respect this sacred time with compassionate presence and dignity for those served.

The NCP (National Consensus Project) defines spirituality as a "Dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred."<sup>4</sup>

As clinicians, an important skill set to develop is refraining from judgement and being open to those entrusted to your care. Empathetic listening and compassion can be a source of hope and strength in even the most difficult moments. Leaning in with sincerity and presence is often a vital link in rapport building and trust. Providing empathetic listening, being attentive and present to patients /family/ caregivers demonstrates compassion. If desired by a family, share in prayer to meet the specific needs to provide comfort and hope. Be attentive and respect the beliefs of those you serve with great compassion.

Spiritual care should be an important assessment performed on all patients, on admission and throughout the illness journey. "Although some may experience spiritual distress, others may have a spiritual transformation or experience spiritual growth and health."<sup>5</sup>

An individual's faith is based on their unique inner strengths and may be as distinct in meaning and value as every individual who holds this concept within. "Spiritual care concerns the total person and recognizes the interdependence and connectedness of mind, body, and spirit. It provides a dynamic resource for healing and wholeness by paying attention and responding to the unique needs, goals, and resources of each care recipient."<sup>6</sup>

Research has demonstrated how nurses trained in spiritual care can help identify a patient/ family/caregiver's need for spiritual support. They can assist in incorporating spiritual support into the care plan and collaborating with spiritual care providers.<sup>7</sup> Spiritual support is essential in providing holistic care and serving those entrusted to our care with respect and dignity.

**Some educational opportunities are provided below for professional growth in spiritual care.**

**ISPEC-** Interprofessional Spiritual Care Education Curriculum (ISPEC- Peds) <https://smhs.gwu.edu/spirituality-health/program/transforming-practice-health-settings/interprofessional-spiritual-care-education-0/>

**Relias Academy** offers **(ISPEC) ONLINE COURSE**

Spiritual education offered through **SCA- Spiritual Care Association.**

<https://www.spiritualcareassociation.org/>  
<https://www.spiritualcareassociation.org/education.html/>

Important Information About the SCA Learning Center

- The Online Learning Center uses a state-of-the-art learning management system
- Earn a certificate of completion and continuing education hours for each course completed.
- The price for Self-Guided Courses is \$145 for SCA members and \$345 for non-members.

**SCA offers two Palliative Care Certificate Courses** to help you deliver quality spiritual care to palliative care patients. Allow 6 months to complete:

- Fundamentals of Spiritual Care in Palliative Care-30hrs
- Advanced Practice Spiritual Care in Palliative Care- 25hrs

The Center to Advance Palliative Care (CAPC) is another great source for educational information, including many resources which support spiritual care. <https://www.capc.org/search/?q=Spiritual+care+education/>

### A Prayer for God's Children

Dear Heavenly Father,

We know you are here with us, that you surround us with your love and grace.

You give a sense of peace and hope, which can only come from You.

God of love, ever caring, stand by us in our times of need. Be our hope and bring us peace.

Watch over your beautiful children and grant them your mercy, healing, and strength.

Help us to trust in You, knowing with full confidence, you have a special plan for each of us.

Keep us strong in faith, hope and love. Guide those entrusted to provide care and support.

Give us courage and strength to support and bring hope and love to your beautiful children and their families. Your children are precious in your sight and beloved to all who know them.

All these things we humbly ask through Christ Our Lord, Amen.

"Let the children come to me, and do not hinder them; for to such belongs the kingdom of God."

~ Luke 18:16

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# The Case For Enhanced, Proactive Professional Grief Care For Pediatric Hospice And Palliative Care Professionals

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In 1983, psychiatrist and hospice pioneer, Dr. Elisabeth Kubler-Ross authored the book, *On Children and Death*. Though she had been asked to write on the topic for years, publishers pushed back asking who would want to read a book about children dying and grieving. Yet Elisabeth had a different take on the topic. Her book would implore readers to consider the thoughts, emotions, needs, and inner spiritual workings of dying children and their siblings, thus positioning the child as the teacher, not the student.

The book also focused on the relationship between the seriously-ill child and their treasured belongings, the child's capacity to understand their imminent passing (often ahead of the parents), symbolic language of dying children, and much more. The publication was ahead of its time because it also exposed what many in the pediatric hospice and palliative care field know to this day: The world largely cannot bear to stare a dying child in the face and is even less tolerant of being in the presence of the inordinate pain and suffering children endure as part of the seemingly unjust nature of pediatric disease.

In short, *On Children and Death* invited readers to explore their own discomfort with the fragility of life while also opening the door to flipping the medical model of traditional pediatric healthcare on its head. In her book and in her work, seriously-ill children were the educators and the voice to be considered in a world where the medical model largely positioned the physician at the top of the professional healthcare flow-chart.

Thankfully, much of that has changed and care teams now often, though not always, provide space for the child to have a voice in their own care and end-of-life experience where possible. But the services available for dying children, their caregivers, and professional care teams is not equal to that for dying adults in most of the world and that inequity is what deserves highlighting as we look toward the future of pediatric hospice and palliative care.

## Case Study:

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In 2005, a 14-year-old child died following 18 days of palliative sedation and the removal of nutrition and hydration which allowed natural death, all guided under the local hospice's direction. The hospice had suggested this course following 11 days of intractable pain and suffering. Following multiple consults with several physician-specialists in the UK and the US, it was determined that the rare disease was most likely taking its course though no one was sure death was imminent.

## Professional care:

For the last 4 1/2 years of the family's 10-year-experience caring for the child with a rare disease, the child received care in the home from a local home healthcare agency. The area hospice oversaw the care and contracted with the agency because like many hospices, there was limited specialized pediatric hospice nursing care available in the region. At that time, the family had two nurses on a rotating shift, each providing three eight-hour shifts per week. Other nurses would fill in where possible, with the brunt of the care placed on the primary custodial parent who was also a single-parent caregiver of another healthy, younger child in the household.

When the seriously-ill child died, one of the two nurses left the field immediately. Shortly thereafter, she entered a residential rehabilitation program for alcohol abuse, stating that her almost-five-years with the child left her feeling emotionally ill-equipped to bear witness to the immense pain and suffering of the child. She then divorced and her fractured family struggled, then regained stability in the ensuing years.

The other primary nurse for the child also left the pediatric hospice field in the months that followed, vowing to never care for a child facing end-of-life again. Her 4 1/2-year experience of observing profound suffering and under-managed pain jeopardized her mental health which led her to seek in-patient counseling out-of-state.

## More Recently

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A few years ago, I gave a presentation on Pediatric Palliative Care at the National Institute of Health (NIH). During the Q&A following the presentation, one of the CEO attendees raised her hand. She asked for input because one of her nurses recently had died by suicide. Her concern, then, echoes what I have heard from other providers in the field throughout my 19-year career. *"What can we do to support our pediatric hospice and palliative care clinicians and teams," she asked as she approached the stage, her eyes filled with tears?" The rest of my team is emotionally spent. It breaks my heart and I also don't want them to quit."*

In another instance, a hospice CEO texted me late one night, politely asking if she could call me. She then shared how she "just can't do it anymore." In tears, she explained how she felt she had failed a family because a pediatric patient had endured a complicated, painful death. She felt her ability to process this family's suffering was beyond her capacity.

Last year, a hospice's seasoned social worker exited the field following a pediatric patient's mother who died by suicide one month after the child's death. The social worker was a cherished and respected professional who couldn't bear to think that she "missed something." There were limited professional grief resources in place and no extended bereavement care for the social worker.

These are just a few of the many professional grief experiences shared with me over the years. Bearing witness to the unique, profound suffering that accompanies children and their family members as they face acute pain and the emotional and spiritual suffering inherent in most pediatric serious illnesses, death, and grief journeys is beyond the scope of expertise for most hospice care providers. The responsibility and role of pediatric hospice and palliative care team member is often a complex, heavy load to carry.

Lanise Shortell, RN, Administrator of Pediatric Hospice and Palliative Care of Georgia shares, "Professional grief is unique. It is disenfranchised grief, in a way. It is a natural human response to grieve the loss of patients we serve. The challenging part is managing professional loss with ongoing personal losses. Our world is in a state of ongoing grief. The compounded impact of professional and personal loss can be too much to bear. Without a fresh lens to emotionally sustain professionals working in the end-of-life space, we will continue to see staffing shortages and poor-quality care when families need our support and clinical excellence the most."

Providers of pediatric hospice and palliative care need a substantial increase in the scope and coverage under the employer-sponsored professional bereavement benefits that correlate to the length of time of service, role, and



responsibility inherent in the provision of care of seriously-ill and dying children and their families. Several hospice executives have shared that pediatric hospice and palliative care nurses receive 1:1 what adult professional providers do under professional bereavement care and services, with little to no expansive conversation surrounding the fact that children are often on service for years at a time. As well, more children are living longer due to enhanced care opportunities and advanced technologies that keep seriously-ill children alive longer. Who is going to care for these children in the months and years ahead?

It's time to reframe what strength looks like in professional grief management. Many employers are implementing self-care/repair into job descriptions and professional expectations.

This may look like increasing PTO days off yearly, allowing paid days or consistent self-repair activities such as massage, yoga, counseling, and/or nature days. This approach includes rewarding employees for self-care activities through yearly evaluations and pay raises. Implementing both cognitive and somatic strategies to manage professional grief is a proactive stance that anticipates and attends to the very real human response to losing patients we care for.

If we are not proactive in our response to professional grief, it becomes compounded until there is no space left for providers to process loss. When unacknowledged, professional grief burns out each member of the IDT team, thus endangering both the families served and the programs that organizations have spent hundreds of thousands (or more) to build.

#### **What does real support look like?**

- Having professional counselors debrief with the IDT monthly
- Monthly outdoor nature experiences with days off allotted to attend these experiences
- Evidence-based yoga and breath work opportunities
- All blended into job requirements

In closing, "unattended grief is at the core of pediatric hospice staffing shortages nationwide," shared Shortell. "Accessible avenues to metabolize professional grief are required to sustain practitioners that sustain the at-risk families we serve."

# Concurrent Care Payor Relationships: Development and Maintenance

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## Introduction

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Implementation of concurrent care through the Affordable Care Act has significantly increased the accessibility of hospice services for medically eligible children and made it possible for hospice providers to offer a higher level of care and support to children and their families with complex medical needs. While the provision requires states to make hospice services available to individuals under the age of 21 eligible for Medicaid and CHIP programs while expecting states to continue to pay and provide disease alerting and/or life prolonging interventions after hospice election, established guidelines on how to interpret and implement this model of care are still lacking. As a result, many programs throughout the country have adapted innovative care models to reflect adult hospice standards and/or hospital palliative care programs, with consideration of concurrent delivery and pediatric nuances. Both the development and adjustment to these care models requires considerable and ongoing networking, relationship building, and collaboration with state, commercial, and private payor stakeholders. The expectations outlined in Provider Services Agreements, Memorandums of Understanding, and other established understandings between the hospice provider and each individual pay source are inarguably the single most important catalyst for the initiation, maintenance, sustainability, and growth of hospice programs who care for children and their families at end-of-life. This article aims to provide an overview framework for hospices seeking to develop and strengthen relationships with pay sources by incorporating specific guidelines for concurrent care implementation, decreasing barriers to care, and improving care quality for mutual patients that have proven effective with a community-based and non-for-profit pediatric hospice program.

## Affordable Care Act and Medicaid

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Starting under the 2010 Affordable Care Act, Section 2302, children enrolled in Medicaid can have curative and/or life-prolonging treatment at the same time as hospice care. Concurrent care allows for children and families to access additional support in an era of changing and increasing prognostic uncertainty for often incurable, progressive, and complex life-limiting conditions. In care application, the hospice provider manages and pays for all services included in the hospice plan of care, with other providers managing needs outside of the hospice plan of care. Section 2302 not only requires state payors to allow concurrent care but expects them to continue to pay for life-prolonging and/or curative

treatments, while still reimbursing the hospice provider at the daily level of care per diem. Beyond an overarching understanding about access to concurrent services and cost responsibility, pathways of implementation, expectations surrounding care delivery, and adjustments to eligibility criterion are determined between the hospice provider and state payor. This often requires additional research and relationship-building between the hospice agency and Medicaid offices to determine ongoing collaboration expectations, points of contact, and concurrent care boundaries for age, treatment, and/or coverage. With ever-changing regulations and hands in healthcare, the establishment and consistent communication becomes crucial in the ongoing relationship with hospice agencies and Medicaid-managed programs.

## Relationship Investment with Pay Source Stakeholders

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The hospice organization must first determine which person, or team, (i.e., "Pediatric Care Coordinator/ Pediatric Champion") will be responsible for managing and nurturing pediatric/concurrent care directed relationships with pay sources. Depending on the knowledge base within the organization, initial efforts may require investment to learn more about concurrent care implementation and care delivery practices. Engaging with hospice organizations with dedicated pediatric programming and acclimating to NHPCO's Concurrent Care Implementation Tool Kit are the best places to start. The following framework has been developed to aid identified "Pediatric Champion(s)" initiate and strengthen relationships with pay sources to decrease barriers to care, improve care quality, and demonstrate financial stewardship in the care of pediatric patients.

### Research of Pay Sources

Through research, the agency can identify both existing and potential pay sources within the service area. Prioritization is a key element in initial research into potential pay sources and their support of concurrent care utilizations. Initial research and development of concurrent care programming should prioritize by:

1. Those with federal directives to honor concurrent care i.e. Medicaid, Tricare as they will likely have programmatic and financial outlines conducive to offer guidance and support in reimbursement and coordination.
2. Payors who insure children as the primary beneficiary for easier accessibility to coverage information and feedback.
3. Commercial payers i.e. Anthem Blue Cross, United Healthcare, etc. and efforts should be directed towards the most frequent pay source for the hospice's patient population and/or pay sources with largest market share in the hospice's service area.

### Understanding of Requirements and Guidelines

Prior to initiating contact with pay source stakeholders, it is essential to understand the existing requirements and guidelines of each pay source, including eligibility criteria, billing processes, reimbursement rates, and if beneficiary election of hospice results in any alterations to coverage benefits. This familiarization should also extend to state-level nuances, as outlined in Medicaid State Plan Amendments. For example, will hospice election alter the plan in any way that could prevent access to treatment or care? This information can be obtained through connection with other local/state-based programs as well as other nationally based models for care. It's also crucial to engage with relevant personnel within your organization (Patient Accounts, Senior Billing/Contracting, etc.) to obtain a copy of each insurance pay rate agreement and Provider Participation Agreement. By gaining access to participating provider resources there is a greater capacity to navigate the needs vs wants re: payor reimbursement and strategy. Additionally, there is the opportunity to gather as much information as possible from online or other resources that include NHPCO toolkits, listservs, and honorable resources such as this e-journal.

### Identify, Engage, and Educate

The hospice agency must identify key pay source stakeholders and initiate contact to begin building relationships. Most often, the insurance case manager and insurance representative (connected with an existing patient) will present the most immediate opportunities for initial rapport building. These individuals are many times the

facilitator of connection to the director of Case Management, Clients Relation Provider, and Medical Director. The "pediatric champion" or coordinator can then begin to offer ongoing education and training to pay source stakeholders about the services and benefits of hospice care, accessibility, value of services offered, and the concurrent care delivery model. This must occur at the individual case management, group case management, and medical director level, often in that order. Ongoing education will be likely as information and personnel are updated. By offering repeated opportunities for discussion, there is a minimization of an immediate denial or shift in policy and can promote a more collaborative environment to continue meeting the needs of the patient.

### Imbedding Payors into Care Models

During the imbedding process, it is crucial to clarify communication channels and expectations of the anticipated partnership between program/agency and payor. While the Provider Participation Agreement acknowledges payment for services can be made to the hospice provider and outlines services covered by the plan, expectations surrounding communication, care delivery expectations, and other nuances specific to pediatric concurrent care are not defined. At the minimum, engagement must occur between the hospice and key stakeholders to:

1. Clarify the processes the hospice must follow when a concurrent care patient is readmitted to the hospital.
2. Establish the frequency of care communication and collaboration between the hospice provider and pay source stakeholders
3. Identify the best point person within the pay source to aide in resolution of concurrent care access and billing related issues and
4. Determine any requirements for special reporting for concurrent care patients. For example;
  - Health Services for Children with Special Needs (HSCSN) DC Medicaid plan requires submission of a "Panda Passport" (i.e., return to hospital plan) prepared by the Children's National Medical Center Inpatient palliative care team for inclusion in the initial hospice authorization submission.
  - Tricare requires the hospice RN Case manager to complete and submit a monthly report on a template specific to Tricare beneficiaries.
5. Establish clear communication channels and intervals for check-ins will help address any issues or concerns in a timely manner and main positive relationships with pay sources.

These expectations can be further outlined in a Memorandum of Understanding if not included in the Provider Participation Agreement. Any changes to the aforementioned would then need to be communicated to all parties involved for consistency.

### Demonstrate Compliance and Quality

Ensuring compliance and high-quality care to patients and monitoring performance outcomes demonstrates effectiveness of service. Additionally, it produces quantified data-driven insights for reimbursements and referrals which not only supports the renewal of the Provider Participation Agreement but builds further trust with pay sources and encourages referrals. At the highest levels of collaboration, opportunities emerge to advocate for:

1. Service pay rate increase; Ex: Quality data demonstrating a reduction in beneficiary re-hospitalizations after hospice election results in major, favorable financial conditions for the pay source. This produces negotiating power for the hospice when broaching conversations with the pay source about increased reimbursement for high-value, cost-effective services.
2. Amendments to the Provider Participation Agreement
3. Adjustments to eligibility criteria that promote earlier access
4. Incorporation of eligibility indicators into the insurer's utilization management framework
5. Development of innovative and effective care models for children with complex and advanced illness

## Ongoing Concurrent Care Management and Collaboration

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The current interpretation of concurrent care adopted by Capital Caring Kids is to provide, at minimum, the basic pillars of hospice care with the intent of maintaining relationships and coordination with the patient's primary care team, specialists, and hospital(s) of choice. In addition, we work closely to provide continued education in the community to better understand how concurrent care can be of benefit to those with life-limiting conditions as we recognize the resiliency, complexities, and ever-changing treatment options that come with pediatric conditions. By doing so, we hope to continue targeting those that have a limited prognosis earlier in their disease trajectory to better provide support and start difficult conversations while also fully engaging the care team in the ongoing management of care and holistic care of the child and family.

Following the traditional hospice model of care, the nurse case manager is the primary conduit for assessment and management of the child's care in the home. Their vantage point provides the opportunity for accurate reporting to other entities for, inclusive of insurance case managers, private duty nursing companies, and durable medical equipment providers. Additionally, in a concurrent and collaborative model, the nurse case manager would further have accessible channels to report updates, concerns, and changes to the child's outside providers (primary care physician, specialists, attending medical director of record, etc.). Capital Caring Kids has developed a model to offer partnership with outside providers in the overall care management in hopes of limiting trips to the specialist office, emergency department, and/or hospital. Knowing that care collaboration can often be time-sensitive and demanding, a delineation of responsibilities for ongoing follow up and reporting has become vital. Given the need for accurate and timely clinical reporting, the nurse case manager maintains the responsibility of following up and coordinating directly with the hospice/attending medical directors and providers while the patient is receiving routine hospice care at home as well insurance case managers should there be question of clinical utilization. The collaboration and coordination with providers, hospital staff, insurance authorization, and other providers has fallen under the development of a Pediatric Care Coordination position to aid in navigating the concurrent care space. This position allows for more flexibility to provide more in-depth education and direction with each child's specific concurrent care policy and utilization while also serving as a main contact for providers and hospitals to interface with as needed. That information is then distributed to the appropriate contact/team member to follow up on as needed, thus allowing the care team to focus on care provided to the patient and family.

## Coordination of Concurrent Care

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Ongoing collaboration and coordination of care is essential in maintaining productive relationships with payor sources and exemplifying the benefits of concurrent hospice care. Maintaining accurate record of treatments, hospitalizations, care team providers, and DME/medications can assist in allocating resources where they are needed most for the family while also representing a fuller, more accurate representation of the child's medical journey.

### Hospitalizations

Hospitalizations can prove to be one of the most daunting aspects of ongoing care coordination with families and can serve as a barrier to electing concurrent care through payor sources. There is a delicate line in honoring the hospice regulations set and maintained for the adult-based population while also keeping in line with a concurrent care model for care. The procedure used by the Capital Caring Kids team provides contact between the pediatric hospice program and hospital systems to navigate that balance. This allows the pediatric care team to maintain consistency with their own schedules while updates and collaboration can be maintained by the point of contact. When a pediatric patient is admitted to a hospital, whether it be for an emergent or planned need, the point of contact provides immediate support in offering updates from the hospice team in current goals of care, medication, and family needs. This ongoing collaboration allows for insight as appropriate to advocate for the patient/family in ways aligned with their journey at home. This may include the coordination with the hospital-based palliative care, primary care, and inpatient care teams. Due diligence is completed when a patient is

hospitalized to ascertain appropriateness for continued hospice enrollment versus discharge secondary to extended hospitalizations at approximately 14 days (about 2 weeks) in accordance with hospice regulation and in agreement/collaboration with the insurance policy recommendations. The current Medicaid-related policies in the DC metro area have maintained agreement to allow ongoing hospice support and authorization during these hospitalizations in good faith that the coordination of care will promote better utilization of services and hopeful decrease in hospitalizations and/or inpatient stay.

Throughout the hospitalization, updates are provided to the hospice care team and discharge/clinical paperwork is obtained at discharge to be reviewed and stored in the hospice medical record for ongoing care management/adjustment. If a child was discharged due to an extended hospitalization, an expedited re-enrollment is facilitated by the hospice team in coordination with both the hospital and inpatient care team. Moving forward, the hospice team continues to encourage and empower families to access 24/7 triage nursing for symptom management and coordination to minimize future hospitalization and update visit frequencies as appropriate. The Capital Caring Kids team has found this to be a successful approach as indicated in comments made by families, providers, and in a noted decrease of overall hospitalizations in the progression of their hospice journey.

### Durable Medical Equipment and Supplies

A benefit offered to payor sources is the division of responsibility for ongoing medical support for the hospice enrollee inclusive of Durable Medical Equipment (DME) and supplies. Although a somewhat difficult area to navigate, a clearly defined list of covered and non-covered items that can be agreed on by both parties will aid in the delineation of financial responsibilities. Pediatric hospice can, at minimum, cover the basic equipment and supply needs mirrored in the adult population including oxygen, hospital bed, and assistive devices for ADLs. However, many pediatric patients referred to and enrolled in concurrent hospice care may come on board with existing DME and supplies in place. At that time, the hospice company can provide opportunities for reconciliation and switch out equipment as indicated or appropriate. In the cases where more specialized equipment is needed, or supplies have been fulfilled regularly, ongoing management would remain in place as it was prior to the hospice admission. The overarching consideration for delineation is carefully considered based on the hospice diagnosis and goals of care. For children in pursuit of concurrent care, curative and/or life prolonging care needs remain managed outside of hospice. For a child in pursuit of comfort care, hospice becomes the managing party for all needs. For concurrent care patients, as care needs progress and goals of care evolve, there may be opportunities for hospices to have more management of equipment whether it be the addition of items or the transition of ownership. There is also always the option to explore supplemental support for supplies to offset any financial obligation for the family. In partnership with payors, this can provide another bridge for accessing the benefits of concurrent care as supply costs can be offset when there is a clear and distinctive need. It is important to keep the lines of communication open with payors and supply companies to recognize individual needs and differences in the plan of care needed for the pediatric patient while also offering ongoing education on hospice management capacities.

### Medication

Medication management is an additional grey area where ownership can be difficult to define. Those medically complex children that are often eligible for concurrent hospice care have high medication utilization and need. Given the regulations followed by hospice agencies regarding the palliation of symptoms, there need to be clearly defined parameters regarding the ongoing management of medication and prescribing when a pediatric patient is admitted onto hospice. In many cases, an initial reconciliation can be completed by identifying if the medication is deemed concurrent vs palliative in nature. Those pain, anxiety, and respiratory medications typically covered by hospice agencies would expect to be managed by the hospice team once enrollment occurs. However, those medications seen as concurrent (even if they are palliative) would need continued oversight by the primary providers. These may include medications such as: preventative treatment, chemotherapy and chemotherapy-related medication, nebulizers, clinical trial protocol medication, and others. Having a clinical champion to help navigate medication management is crucial to promote consistency in coverage across the board.

Pain management is a role typically taken on by the hospice team. However, it is common for referred pediatric patients to have an established pain management routine in place. Open and transparent conversations need to be ongoing between the primary team and hospice team regarding pain management with the hope of enacting a one-prescriber system to decrease concerns of misuse or divergence while also honoring a payor's request for appropriate allocation of resources to the hospice team. In most cases, controlled narcotics used for pain management should be logged and reported to all providers for awareness with one-prescriber (typically the hospice physician) taking on management. If possible, a contract should also be established with the family while on hospice services to promote educated, appropriate, and safe use. This combined will help improve communication with patients and other providers, mitigate/palliate the pain while on hospice services, and hopefully improve the function and quality of life to limit (CDC 2023) the need for ongoing hospital and/or ED visits.

## Conclusion

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Though the interpretation and utilization of concurrent hospice care can vary state-to-state, the establishment of relationships, expectations, and coordination remain a vital part of how hospice is offered to children nationally. The fundamental collaboration between agency and payor can set programs up for success and, hopefully, promote longevity in accessing end-of-life care for the pediatric population.

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# 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](mailto:Christy.Torkildson@gcu.edu). Thank you.

- Pediatric Palliative Care Webinar Series for 2024 has been announced. Calendar and more information, including how to register can be found at [www.ppcwebinars.org](http://www.ppcwebinars.org)**
- NHPCO Releases 2024 Pediatric Palliative and Hospice Care Needs Assessment**  
Are you a hospice or palliative care provider or organization who has cared for at least one pediatric patient during the last four years? If so, complete the [2024 Pediatric Palliative and Hospice Care Needs Assessment](#). The Needs Assessment is a product of the National Hospice and Palliative Care Organization's Pediatric Advisory Council with the goal to gain a better understanding of the organizations and providers caring for pediatric patients with serious illnesses throughout the United States. The needs assessment helps create resources and support advocacy. You do not need to be an NHPCO member to complete the survey. Any questions can be directed to the Pediatric Advisory Council at [pediatrics@nhpco.org](mailto:pediatrics@nhpco.org)
- Attend NHPCO's Pediatric Webinar Series**  
Join the faculty for a [two-part webinar miniseries](#) that will cover the journey of pediatric hospice and palliative care from its history to envisioning a holistic, patient-centered future, as well as introduce a toolkit to help providers navigate coverage for concurrent care with private insurers for pediatric patients. Each webinar will be held on May 9 and May 23 from 2 p.m. to 3 p.m. ET and will be 1 hour in length.
- UPCOMING Conferences:**
  - The 2024 NHPCO Leadership Conference will be in September 2024.  
More information can be found [on the NHPCO website](#)
  - **Have a conference to submit/share – send us the information to [Christy.Torkildson@gcu.edu](mailto:Christy.Torkildson@gcu.edu).**
- Subjects and Contributors for Future Issues of this E-Journal**  
Our future issues will be centered on the following main themes. If you have any thoughts about these or any other topics, contributors, or future issues, **please contact Christy at [Christy.Torkildson@gcu.edu](mailto:Christy.Torkildson@gcu.edu) or Melissa Hunt at [melissa.hunt@optum.com](mailto:melissa.hunt@optum.com).**

## Issue Topics: 2024

- **Let us know your ideas!** What topics would you like to see addressed in the Pediatric e-Journal? Issues will be distributed in February, May, August, and November.
  - **Issue #76:** Social media, technology, communication
  - **Issue #77:** Home Care
- NHPCO Pediatric Website Pages have been updated for easier searching!**  
**NHPCO Palliative Care Online Resources:** NHPCO has a variety of pediatric hospice and palliative care resources available at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics). Also, more palliative care resources are available at [www.nhpco.org/palliativecare](http://www.nhpco.org/palliativecare), including:
    - Community-Based Palliative Care
    - Legal and Regulatory Resources
    - Webinars and Courses
    - Brochures in English and Spanish for families
    - Plus, more for NHPCO members



7. **Questions about Concurrent Care?** Dr. Lisa Lindley and her team have created a wonderful website full of resources and information. You can access all the information for **Pediatric End-of-Life Care Research** at <https://pedeolcare.utk.edu/>
8. **Palliative Care Programs and Professionals:** Founded in 1978, National Hospice and Palliative Care Organization (NHPCO) is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families. [Join NHPCO Today!](#)  
[Individual Palliative Care Membership](#)  
[Palliative Care Group Application](#) - Save by registering your entire team

**Note:** Many of the pediatric resources are open access as a community service by NHPCO and membership is not required. However, we would love to have you join our community of vested professionals focused on quality palliative and hospice care throughout the lifespan!

**Do you have a resource that would be helpful for others to know about?** Please send the information to **Christy** at [Christy.Torkildson@gcu.edu](mailto:Christy.Torkildson@gcu.edu) and we will add it to the Items of Interest.

## Previous Items of Interest

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9. **Did you know that the State Coalitions from Pennsylvania, Illinois and California, with support from the Shiley Haynes Institute for Palliative Care and the HAP Foundation,** host monthly, affordable webinars with continuing education units available? You can register for one or the entire series, with discounts for multiple registrations. For more information, review the [PPC website](#).
10. **On that same note, did you know there was a network of state coalitions and folks interested in helping with or starting a state coalition for Pediatric Palliative Care?** For more information, contact **Betsy** [betsy@ppcc-pa.org](mailto:betsy@ppcc-pa.org)
11. **End-of-Life Nursing Education Consortium (ELNEC) project** has several upcoming courses; if you are faculty, you can get free access to the curriculum for your program/courses you teach.
12. Recently, the **California Advocacy Network for Children with Special Health Care Needs** announced their foundation had committed to increasing access to journal articles that may be difficult for family members and non-profit staff to access to improve "effective and equitable systems" as "access to scholarly work is essential to system improvement." More information can be found on the [California Advocacy Network for Children website](#). It may be helpful to contact your state's chapter to determine what resources they may have!
13. **Courageous Parent's Network** has a wealth of resources for parents, caregivers, and providers. The list is too long to add here so please check out [CPN's website](#).
14. **The Pediatric Palliative Care Coalition of Pennsylvania, the Greater Illinois Pediatric Palliative Care Coalition, and the Funeral Service Foundation have created a community resource to guide families through the funeral/memorialization planning process:**
- When a Child Dies: Planning Acts of Love & Legacy***
- This resource is available in both English and Spanish and is **FREE**, thanks to generous funding from the Funeral Service Foundation. You pay only a nominal shipping fee. More information can be found at [When A Child Dies](#).
15. **Pediatric Go Wish Together:** A conversation game for parents and pediatric caregivers; developed by Meghan Potthoff, Ph.D., APRN-NP, PPCNP-BC, CPNP-AC in collaboration with Coda Alliance. This game is "developed to help parents navigate the unimaginable journey of their child's illness." "It is a tool that provides parents and providers a way to think and talk about what's most important to the child". More information can be found at [Pediatric Go Wish Together](#)

- 16. Have you heard of the new organization PallCHASE: Palliative Care in Humanitarian Aid Situations and Emergencies?** Their primary ambition is the relief of suffering, and their purpose "To work in partnership through a visible and effective network to advocate for palliative care integration in humanitarian situations or emergencies...". Please visit their website for more information, healthcare professional training and resources in a variety of languages! Check out [their website!](#)
- 17. Another great new group is the Child Life in Hospice and Palliative Care Network, which provides child life specialists working in hospice or palliative care access to resources, education, research, and networking opportunities to establish and provide best practice care for patients and families experiencing a serious illness.** They are requesting that interested members fill out a brief survey, sign up today at [CLHPN](#)
- 18. A Toolkit of Autism, Grief, and Loss Resources by Hospice Foundation of America**  
The [toolkit](#) will include a variety of materials and resources, such as:
- suggestions for responding to the grief experiences of autistic adults;
  - ways to provide for choice and inclusion in rituals;
  - tips for communicating the news of death;
  - social stories on grief for adults;
  - videos about grief, including interview clips with autistic adults and their families;
  - two complimentary continuing education (CE) programs for professionals; and much more!
- 19. A resource for pregnancy or infant loss is [Share: Pregnancy & Infant Loss Support](#).** Share was started in 1977 in response to the urging of one bereaved family by Sr. Jean Marie Lamb, OSF. Initially providing support groups, they now offer online support groups, education, and support for families and caregivers.
- 20. The Pediatric Palliative Care Coalition of Pennsylvania (PPCC) has made a new resource available – a Sibling Grief and Bereavement Toolkit.** This Toolkit has been developed to address the needs and concerns of children and teens who have experienced the death of their sibling with medical complexities. Please see the associated article in this edition! Below is a link to the toolkit and one of the activities – "Make a Feelings Chart".  
[View the PPCC Sibling Grief and Bereavement Toolkit.](#)

### Toolkit Activity

For children who are grieving the loss of their siblings, returning to school can be a difficult transition. Check out this month's highlighted activity from the toolkit that may help children and teens in the upcoming school year.



Make a Feelings Chart by [downloading the activity](#). PPCC invites you to share this information with parents, caregivers, medical professionals, providers, therapists, etc.

### 21. Pediatric Hospice and Palliative Care Resources:

- **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. [www.caringinfo.org](http://www.caringinfo.org)

**NHPCO's Palliative Care Resource Series includes pediatric palliative resources like:**

- Communication Between Parents and Health Care Professionals Enhances
- Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy
- Consideration for Complex Pediatric Palliative Care Discharges

- Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and Hospice Care
- Nonpharmacological Pain Management for Children
- Sibling Grief
- Pediatric Pain Management Strategies
- Communicating with a Child Experiencing the Death of a Loved One: Developmental Considerations
- In an effort to standardize the medication coverage process for children receiving concurrent care, the NHPCO Pediatric Advisory Council developed a new resource for providers titled
- Determination of Hospice Medication Coverage in CHILDREN.

## 22. Trends in Pediatric Palliative Care Research

Every month, PedPalASCNET collects new pediatric palliative care research. For past lists visit their blog, browse in their library, or join the Zotero group. View the New Citation List in their library.

## 23. Palliative Care Resources for Nurses, Patient Care Support Staff, and Families of Patients by Life and Death Matters, <https://lifeanddeathmatters.ca/>

offers texts, workbooks and resources for providers and family members. Although primarily focused on adults they reference across the lifespan with sound principles that are useful no matter the age of your patients.

The text, workbook and companion resources support nurses and nursing students (in Canada and USA) to develop the knowledge, skills, and attitudes for integrating a palliative approach and providing excellent end-of-life care.

### **Essentials in Hospice and Palliative Care: A Practical Resource for Every Nurse**

Textbook: 978-1-926923-11-6 | Workbook: 978-1-926923-11-6

<https://lifeanddeathmatters.ca/product/palliative-care-nurse/>

The text, workbook and resources, based on national competencies, will help nurses:

- Develop best practice interactions
- Decrease fears and increase confidence and competence in caring for the dying person and family
- Develop ethically and culturally competent practices with touchstones and by relating experiences

**Also available for this title:** Videos, Podcasts, PowerPoint™ Presentations and NCLEX-style questions

Please note the archived issues are available as a community-service by NHPCO and can be found at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics) or by reaching out to [Pediatrics@nhpco.org](mailto:Pediatrics@nhpco.org).



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