

**EDUCATION AND TRAINING RESOURCES FOR ADULT PALLIATIVE  
AND HOSPICE CARE PROVIDERS AND PROGRAMS WHO ARE  
CALLED UPON TO CARE FOR A CHILD AND FAMILY**

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# Pediatric e-Journal

**PEDIATRIC ADVISORY COUNCIL**

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**NHPCO**  
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# Pediatric e-Journal

## Pediatric Palliative and Hospice Care

Issue #72 | August 2023

### Issue Topic: Education and Training Resources for Adult Palliative and Hospice Care Providers and Programs Who are Called Upon to Care for a Child and Family

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Welcome to the 72nd issue of our Pediatric e-Journal. In our last issue, we focused on education and training resources for providers and programs that are already involved in the delivery of pediatric palliative and hospice care. In this issue, we concentrate on education and training resources for providers and programs that are currently working in the delivery of adult palliative and hospice care, but who may find themselves called upon to care for a child or adolescent and those young people's family members.

Our goal in this issue is to bring together as wide a range of education and training resources as we can draw together in a single issue. Once upon a time, there would have been few education and training resources of this type. Now there are many and we decided it might be useful to gather together as many of them in one convenient source.

At the same time, we also want to encourage providers of adult palliative and hospice care not to shy away from a youngster and that person's family members who may be in great need of their care. There may be many reasons why such a call might arise and it may seem daunting when first asked to enter into a pediatric situation. However, we hope the contents of this issue will show that there are resources that can guide the way and pediatric colleagues who will be happy to offer support and assistance if they are only asked.

We do not expect that a single issue of our e-Journal will cover every possible education and training resource to assist adult providers that are called upon to help in pediatric palliative/hospice care, but we hope to guide readers to as many of them as possible, with emphasis on those that are most prominent and most useful—and perhaps to draw attention to some that may be less widely known.

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 Suzanne Toce. Chuck Corr is our Senior Editor. Archived issues of this publication are available at [www.nhpco.org/palliativecare/pediatrics/](http://www.nhpco.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 currently discussing the topic of multidisciplinary approaches to pediatric symptom management for our last issue in 2023, but we are wide open for our four issues in 2024. If you have any thoughts about potential topics for future issues or contributors, please contact Christy Torkildson at [Christy.Torkildson@gcu.edu](mailto:Christy.Torkildson@gcu.edu) or Suzanne Toce at [tocess@gmail.com](mailto:tocess@gmail.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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### **Shadow Dancing + Death and Life**

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*Scott Newport and McKenzie Rose Stothers*

Long-time readers of this Pediatric e-Journal will be familiar with Scott Newport's many contributions and his extraordinary good work in supporting families who are challenged by being called on to care for a child with a life-threatening/life-limiting condition or who have had a child die. Here Scott introduces us to a distinctive and charming essay on "Death and Life" written by a 15-year-old girl who has for many years been struggling with a life-threatening condition. We are grateful to Scott and to McKenzie and her parents for giving us permission to include her essay here.

### **Important Tips for Caring for a Child When You Are an Adult Hospice/Palliative Care Service**

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*Ann Fitzsimons, BS, MBA, with Members of the Pediatric e-Journal Workgroup*

Here is a single-page collection of suggestions from one of the most experienced members of our Pediatric e-Journal Workgroup with additional ideas from other members. This short synopsis offers practical advice and resources to use in implementing that advice.

### **Adult Providers Caring for Pediatric Patients**

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

In this article, Dr. Misner draws attention to the great need to enlarge the pool of caring for pediatric patients. While not denying challenges in accepting this responsibility, he notes that "The same basic medical principles still apply, which include the need to demonstrate attention to detail, the desire to serve when called upon, and the willingness to demonstrate love and compassion to those who are often in their most vulnerable state." His plea is to those who "have the ability and desire to step up and give assistance when needed," and he points to many resources can help those who are willing to do so. Dr. Misner's conclusion is simple: "You CAN do this. Assistance is available to help you achieve success and the children will make you feel like a champion while doing so."

### **What Do You Do When You Don't Know What to Do? Caring for Seriously-ill Children**

p. 9

*Weston L. Rice, MSN, ACNP*

This article begins by drawing on an NHPCO survey to point out that "there is not one robust pediatric program in every state and that rural or resource-barren areas may have limited staff with pediatric expertise. Many programs and providers are challenged when caring for children due to insufficient resources, lack of pediatric trained staff, and the need for pediatric continuing education specific to child development, pharmacological management, and pain assessment." Still, the author suggests the value of knowing the available resources in your community and the great importance of communication. He advises interested parties to seize opportunities for pediatric-specific education and he concludes with a recommendation to "establish and invest in a core team with access to community experts."

### **My Recipe—Not the Only Recipe**

p. 11

*Pat A. Frasca, CLS*

In this article, an experienced child life specialist who has worked in a variety of settings asks readers “to explore the ways you communicate with your patients and their families. My first suggestion is to bring your best genuine self into the room. Don’t try to be someone you’re not.” She continues by adding, “Building a trusting relationship begins the moment you walk in the door. First impressions matter, and it’s important to remember that you are not the only one doing an assessment.” A third piece of advice is “Always assume your patients are listening even if they are immersed in play or sleeping.” There is more, including the concluding analogy of a daffodil, which is similar to the familiar hospice diagram of an interdisciplinary team.

### **Key Considerations when Working with Parents of Children with Serious Medical Conditions**

p. 13

*Chrissy Salley, PhD*

This article by a representative of Courageous Parents Network offers the perspective of parents about what they need from the clinicians who care for their children. These children are likely to present with a wide range of serious disease types, often with less clear prognoses and life expectancies. What do such parents want? Recognition of: their role as caregivers (in most situations); the substantial emotional and practical burdens they are bearing; and their existential distress. Realization that “care is in essence being provided to the entire family” and that emotional and other reactions are a normal part of anticipatory grief. Above all is “the importance of building a trusting and honest relationship between the caregivers and the clinicians,” which is fostered by examples given here of good communication and appreciation of the positive value of hope.

### **POLST or MOLST, Advanced Care Planning, and Pediatrics**

p. 16

*Christy Torkildson, PhD, RN, PHN, FPCN, and Oralea Marquardt, LCSW*

A critical instrument when engaged in advanced care planning with patients and their family members is the POLST (Physician’s Orders for Life-Sustaining Treatment). Because this document is regulated by state legislation, it may have different names and slightly different features in different states. This article explains the general characteristics of the POLST, shows how it can apply to pediatrics, identifies its advantages, offers links to obtain more information, and uses a case example to illustrate how a POLST might be used.

### **Adapting an Adult Hospice Inpatient Unit to Meet the Needs of Pediatric Patients**

p. 19

*Oralea Marquardt, LCSW*

This article is the first of three that describe how adult hospices adapted their inpatient programs to care for pediatric patients. In this case, the program conducted focus groups “to identify chief concerns that prohibited the ease of access to the IPU for pediatric patients, to brainstorm ways to address and overcome those concerns, and to ensure the high-quality care of pediatric patients during their stay at the IPU...three key themes emerged: (1) operational needs; (2) hesitancy of adult-focused nurses to care for pediatric patients; and (3) the emotional distress on staff that accompanies caring for pediatric patients at end-of-life.” The article describes how these concerns were addressed and concludes that “The continued collaboration and willingness of all professionals involved to learn is paramount to this endeavor.”

### **A Person is a Person No Matter How Small**

p. 22

*Amber Ash, LISW-S, LMSW, and Michelle Miller, LISW-S, ACHP-SW*

Here is another description of how a hospice program arranged to have adult hospice nurses care for pediatric patients, this time in a hospice house setting. The article explains that the pediatric team meets with those nurses before admission, an “All About Me” poster is prepared to display above the child’s crib or bed, training is conducted on “the delicate balance of child-centered care, maintaining boundaries, and respecting care decisions.” In addition, the importance of confidentiality is stressed, the pediatric team is available and makes regular visits, and throughout “the pediatric team recognizes the need to prioritize the emotional well-being of staff members providing care to pediatric patients.”

### **Caring for Pediatric Hospice Patients from the Perspective of Adult Hospice Care Practitioners**

**p. 24**

*Michelle Goldbach, DNP, MHA, RN, NEA-BC*

Here is a third example of what an adult hospice program did to meet the needs of staff when expanding its program to take on care for pediatric patients and their family members. First, an introductory module addressed fears, concerns, questions, and even resistance on the part of all staff who would be involved, regardless of their role in the agency. A useful tactic invited everyone to write as many concerns as they wished on post-it pads, pasted them on a wall, and then addressed them one by one. "The most common worry and hurdle turned out to be not knowing if they could handle their own emotions." This needs time to attend to and ongoing support. "[T]he next step would be providing more extensive classes in pediatric hospice and palliative care either developed by the pediatric team or using a program that already has been developed." Beyond that, when hiring new staff, letting them "know up front that they might be asked to care for children is a must to prevent future issues." Finally, "For the long term, continuing to provide annual educational sessions and precepting in the field is key."

### **The Pediatric End-of-Life Information Online: An Overview of the PEDEOL Care Research Group Website**

**p. 28**

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

This article describes a comprehensive website focused exclusively on pediatric end-of-life care that is continuously updated with research, policy, and education materials, and is available without charge for anyone from which to benefit. The site provides research, advocacy, and education/training information. The authors write: "The resources and tools provided on the site are evidence-based and verified so that the information is readily available in easy-to-use and read formats."

### **Support of Hospices in Caring for Pediatric Patients in Washington State and the NWPPCC Region**

**p. 30**

*Anne Anderson, RN, CHPPN, and Barb Hansen, MA, RN*

This article is the first of two that describe regional collaboratives on behalf of pediatric palliative and hospice care. In this case, it is the activities of the Northwest Pediatric Palliative Care Coalition (NWPPCC) for the States of Alaska, Idaho, Montana, Oregon, and Washington that are designed to "help provide education, advocacy, and peer support throughout the region for pediatric palliative care and hospice." The article offers an "example of a successful relationship with a hospice that primarily serves adults...[a relationship] between Seattle Children's Hospital Palliative Care team and Hospice of the Northwest. This hospice serves a large geographic area" that is mainly rural and some of which is only accessible by ferry. A series of closing thoughts come from two medical directors in the form of helpful advice and suggestions.

### **REACH Initiative: Regional Pediatric Education and Assistance Collaborative for Hospice Nurses**

**p. 33**

*Taylor Aglio, MD, Med, and Ashley Autrey, MD*

This is the second article on a regional collaborative, in this case one that arose from "A previous population-level survey of hospice nurses across Tennessee, Arkansas, and Mississippi [that] demonstrated that the vast majority of nurses lacked training in pediatric palliative or hospice care, overwhelmingly felt uncomfortable caring for children, and emphasized the urgent need for pediatric-specific training." The response was to establish a Community Advisory Board to work collaboratively with a Strategic Planning Council "to conceptualize and develop a model to provide hospice nurses with access to pediatric-specific training and support." As a result, "free monthly tele-education sessions are provided to nurses who can also earn continuing education credits for attending." The article identifies the 12 topics in the REACH curriculum, the launch of the project in September 2022, and plans for next steps.



### **Pediatric Medication Management Considerations**

**p. 36**

*Melissa Hunt, PharmD, BCPPS*

This article is a detailed guide to pharmacological management of pediatric issues presented by our resident expert in pediatric palliative and hospice pharmacology. The text addresses the following topics: medication dosing, medication management, pharmacokinetics, pain medication considerations, nausea and vomiting considerations, constipation considerations, secretion considerations, and comfort care kits. The article is supported by four tables and an extensive list of references.

### **Pediatric Grief and Bereavement Resources**

**p. 45**

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

Here is a quick two-page synopsis of some useful resources to help you address a child's grief and bereavement. The text includes brief lists of organizational resources, published guides and books, bereavement camps, and online sites.

### **Items of Interest**

**p. 47**

# Shadow Dancing

**Scott Newport**

Evan's father

[scotthnewport@gmail.com](mailto:scotthnewport@gmail.com)



*Two weeks ago, Linda, the pediatric hospice and palliative social worker emailed me and said, "Scott, Dale's daughter just read me this beautiful story she wrote and I am wondering if you may help us to get it published."*

*Over the last few months I have been working with Dale S. He is the father of McKenzie. She is 15 years old and is enrolled in hospice. I am a mentor for parents in palliative care.*

*After reading the story, I met McKenzie and we started the work of revising and editing. We met twice, each time on a Thursday afternoon. I sat in a small cushioned chair next to her bed where I would occasionally have to adjust the oxygen tubing draped over her blankets and snaking up from the lower level of her home.*

*Below is the finished piece, what a privilege for me and hopefully you, too.*

## Death And Life

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**McKenzie Rose Stothers**

[hermajestyqueenrose@gmail.com](mailto:hermajestyqueenrose@gmail.com)

In the middle of the night, a shadow loomed about. Most won't say it but he is also identified as Death. The slinking shadow was from a cloaked being quietly peering as Life freely moved all about. In this story, Life is a woman with short blond hair and a gown that ripples with every breath spoken on earth. Death was sure she was mocking him or so he thought.

The next morning, Death watched as a young couple discovered a lifeless kitten at the edge of the road, which Death had just laid on the damp concrete.

Before dawn, Death had found the young cat happy and blissful. He desired to feel those emotions too, so he touched the tiny creature and soon it started moaning and crying in pain. Scared of what he did, Death quickly picked up the kitten and put it where he thought a human might find it. And then he fled back into the arms of the forest's darkest, tangled roots.

A car soon pulled over and a man could be heard saying, "Look, honey, at this poor kitten. Where do you think its mother is?"

"I don't know. We need to get it help. Death has done enough to it already," the woman said as they rushed off.

As they took the small, fragile kitten into their arms and drove away, Death sighed and kept going through the dark, unnoticed.



"I don't know why that happened," Death repeated over and over.

In his mind, he struggled with, I didn't think Death killed like that—that I killed like that. I just thought I would somehow get this feeling and see someone was in pain and needed to be free from it. Then I would carry them to wherever else they were supposed to go.

"Life has a much better job than I," Death whispered, floating through the shadows, feeling unseen, never touched nor loved; only feared.

From a distance, Death could see the animal hospital and a human hospital. The couple was getting out of their car and that's when He first saw her—Life. She was beautiful, graceful, and kind, as well as content, something Death knew nothing about.

Life floated through the walls and found the kitten. She started gently petting its fur coat and the kitten started purring and was soon fast asleep in the corner of the treatment bed.

"May you live a long life until Death is ready to come for you and bring you back to your mother and siblings," Life said. She then went back outside, spreading her beauty and happiness onto everything she touched.

Death continued to watch from afar as the husband and wife set their newly adopted pet got into the car. But before they left, the vet came out of the hospital. "This kitten is lucky for you to have been there or Death would've taken her for certain. Please look out as Death can take you by surprise any day," he said and went back into the hospital.

"I don't want to be Death! I'd rather be Life!" He screamed. The shouting was so loud it came to the ears of Life, who had just brought a newborn girl into the world.

Not too long after that, Life floated through the forests and trees, smiling as the leaves tickled her fingers and toes. After crossing the highest mountains, she got to the edge of the world, where Death was hunched over, envying Life.

"Death, you and I have been here longer than anyone," Life spoke. Death looked up and they locked eyes and Life said, "I think you know that, if you were Life, the world wouldn't operate as it does." Life continued: "This world and all the others need both of us—Life and Death, new and old, sadness and happiness—as nobody would be content with a forever life. Everyone in this universe and the next need both of us. They need both sides of the coin. And if you continue the way you have been, all will be fine. I promise you."

As she spoke, her eyes revealed to Death all the wonders of life and the beauty of love.

Angry and scared, Death shouted, "But everyone hates me!"

"I don't think that's true. I'll show you. Follow me."

And so, Life and Death went into the local hospital to find an old man with many hospital tubes and an IV, moaning in pain.

"Please, Death, take me into the afterlife. Take this pain from me. I don't have any other use here. Please take me away from this place!" he cried in earnest.

"Go on. Be his hero," Life nudged with a grin. "This is your day."

Death tiptoed up to the bed and said, "I heard you calling. I'm Death. I hear you're ready to come live with me in the afterlife. You will be able to make it whatever you want." Even though Death was trying to speak in a grim voice, he sounded sincere.

"Please, just take me away from this horrible place!" the man gasped.

"Let us depart," Death encouraged. He then grasped the old man's wrinkled hands within his own and let his spirit go free.

"Thank you, Death! You don't know how grateful I am and never will know! I can finally join the rest of my family. You are my hero," he said as he drifted up into his blissful afterlife.

Death left the old man and went to find Life. But when he went to where Life had been standing moments before, she was no longer there. But her voice echoed over the tops of the mountains: "I'm proud of you, Death. And, you know, even though you are Death, Death was born; even Death is alive in a way." And with that, she was gone once again.

Death went back to his home and the familiar, dark cobblestone streets, but he knew that, just like Life said, Life was everywhere; even in Death. And he now knew Life was not mocking him, had never mocked him. She was his other half and he was loved.

.....  
**The end**

*It was a sacred moment when she read this out loud to Linda and me. I kept nudging Linda trying to communicate that I can't believe how freely and animated she is with her voice.*

*I told McKenzie some publishers may change a few things, like the title.*

*She perked right up and said, "I don't mind a few things but I will never allow the title, 'Death and Life,' to be changed."*

*I couldn't help but think about us in the field of helping very sick kids and how often we wish we could change the title or not even have to talk about it. Thank the Lord she isn't willing. I hope this story will help others to be OK about talking about death, too. Her stubbornness of changes was so refreshing coming from an up and coming author.*

# Important Tips for Caring for a Child When You are an Adult Hospice/Palliative Care Service

Ann Fitzsimmons, BS, MBA, with Members of the Pediatric e-Journal Workgroup

You're an adult hospice and you've had a child needing hospice or palliative services come into your care and you're not sure what to do. You've got adult care down, but your staff isn't as knowledgeable or comfortable with taking care of kids.

Some tips to help you on what to do from your pediatric palliative care/hospice colleagues in the field who care for these children every day:

## ■ First, don't panic!

You and your staff can do this!

## ■ Second, take a breath.

You and your staff know more than you think you do. Your skills will transfer in many ways. Let that muscle memory kick in.

## ■ Take an inventory of your knowledge and skills, as well as equipment needs.

- You may wish to enlist in some pediatric sponsored skills courses such as Pediatric Advanced Life Support (PALS) for older children.
- PALS is offered through the American Heart Association (AHA): <https://elearning.heart.org/course/426>
- The NRP (Neonatal Resuscitation Program) is beneficial if you anticipate having newborns and infants in your practice. NRP can be accessed through the American Academy of Pediatrics (AAP) website: [www.aap.org/en/learning/neonatal-resuscitation-program/](http://www.aap.org/en/learning/neonatal-resuscitation-program/)

## ■ Review concurrent care in your state.

Spend a few minutes reading about [concurrent care in your state](#). Unlike adults, children can receive curative treatments/care and palliative/hospice care at the same time. They do NOT have to choose one over the other.

## ■ Expand your network.

Reach out to the closest health system, clinic, service, or hospice you know cares for pediatric patients. While protecting the confidentiality of the patient, explain their case and get any counsel you may need. Ask if they're willing to be open to ongoing communications if you need a safety net while caring for the child.

If you don't have anyone close you can reach out, try the closest [pediatric palliative care/hospice coalition](#) to you. Most will be happy to connect you to a provider who can help answer any questions you may have.

## ■ Remember you have two patients—the child AND the family.

Talk to both of them. Most children want to be involved in their care and care decisions. Children know and understand more about their disease than you might think.

## ■ Use the tools at your disposal.

Like with adults, you have a lot of tools to help care for the child at your disposal. Use what makes sense, but also know for pharmacologic interventions, for example, you may need help adjusting the dosages down for the weight/height of the child. Children are not little adults. A call to a local pharmacist may be able to help here. There is a medication guide as part of the pediatric resources on the NHPKO pediatric webpages.

Additionally, there are resources for advance care planning and establishing goals of care for pediatric and adolescent patients, such as My Wishes for children and Voicing Your Choices for adolescents, [www.fivewishes.org/for-myself/](http://www.fivewishes.org/for-myself/)

■ **You are not alone - there are many resources to assist you!**

## Helpful Resources:

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**Some resources to use that are referenced in these Tips include:**

- Concurrent Care Act: [www.nhpco.org/palliativecare/pediatrics/pediatric-concurrent-care/](http://www.nhpco.org/palliativecare/pediatrics/pediatric-concurrent-care/)
- Pediatric End-of-Life Care Resources, including state by state resources for concurrent care, palliative and hospice advocacy: <https://pedeolcare.utk.edu>
- List of regional or statewide Pediatric Palliative/Hospice Care Coalitions: [www.ppcc-pa.org/advocacy-2/statewide-ppcc-coalitions](http://www.ppcc-pa.org/advocacy-2/statewide-ppcc-coalitions)

**You can also find good information to help you care for this child at the following websites:**

- National Hospice and Palliative Care Organization - Pediatrics: [www.nhpco.org/pediatrics/](http://www.nhpco.org/pediatrics/)
- Courageous Parents Network: [www.courageousparentsnetwork.org](http://www.courageousparentsnetwork.org)
- National Organization for Rare Disorders (NORD): [www.rarediseases.org](http://www.rarediseases.org)
- Pediatric e-Journal, a project of NHPCO; List of additional resources included in the May, 2023 issue, which can be found at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics). Membership is not required. Subscribe or access open access archived issues; available as a community service by NHPCO.

If you want additional information and support, reach out to the NHPCO Pediatric Advisory Council at [pediatrics@NHPCO.org](mailto:pediatrics@NHPCO.org).

# Adult Providers Caring for Pediatric Patients

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As providers for pediatric patients, we understand that children are not “little adults” (Gillis & Loughlan, 2007). In other words, one must consider the fact that physiologically children behave differently than adults, do not necessarily act of their own accord, and often are more affected by environmental circumstances. Consequently, attention to accurate dosing is relevant and meeting the psycho-social needs of both the patient and their extended family members becomes paramount. This holds especially true when dealing with children who suffer with chronic illnesses in either palliative care or hospice settings. Increased suffering often begets more suffering, and each provider can successfully intervene to make a better treatment outcome more feasible. All providers, including those who mainly serve the adult population, can make a difference regardless of the level of prior pediatric experience that they might have. The same basic medical principles still apply, which include the need to demonstrate attention to detail, the desire to serve when called upon, and the willingness to demonstrate love and compassion to those who are often in their most vulnerable state.

Providing accurate care to pediatric patients is essential for upholding the expected standard given to this particular patient population. Remembering the fact that children process medications differently than adults is a step in the right direction. One group of researchers reminds us that, “Both the safety and efficacy profiles of medications may be significantly different for children than adults due to differences in developmental physiology, disease pathophysiology, or developmental pharmacokinetics and pharmacodynamics” (Klassen et al., 2008). In other words, a provider cannot assume that giving any medication including morphine is the same for both adults and children. The reason for this is multifactorial but one prominent theory is that all groups of children, especially infants, have some risk for impaired renal clearance of morphine metabolites. One study demonstrates that total morphine clearance of M3G, which is the predominant metabolite of morphine in young children, is only approximately 80% that of adult values by 6 months (Bouwmeester et al., 2004). A provider should also apply this same thoughtful consideration when prescribing other classes of medications to children such as benzodiazepines.

The key takeaway is that one should seek to learn how to properly prescribe medications for children, in a palliative or hospice environment, while balancing any underlying fear of the unknown. Giving attention to detail, while also avoiding the reluctance of prescribing the meds in the first place, will help to instill confidence in one's skill level. Furthermore, we as providers must try to distance ourselves from the invalid notion that children somehow physiologically tolerate pain better than adults and, therefore, do not need treatment as often as their adult counterparts. One important study in 1986 gives credence to the fact that children do in fact regularly suffer pain crises and further mentions that we should seek other ways to assess pain in the pediatric group. Physiologic cues such as increased heart rate, respiratory rate, and blood pressure should be noted in young children (Schechter et al., p. 5). Following these clues will enable anyone the opportunity to prescribe medications more judiciously and to gain knowledge while doing so. With time one might hope that educated providers will then seek to pass on this newfound understanding to other practitioners and thus uphold the old adage of “seeing one, doing one, then teaching one.”

As a profession, medical providers usually have the ability and desire to step up and give assistance when needed. Currently there is a definite need to provide care for children who require hospice and palliative care. The need, however, is not fully met under the current conditions and many children are not receiving care in order to help

alleviate their suffering. For instance, it is estimated that only 40% of community-based hospices provide care to children, and most home hospices feel ill-prepared to care for children. Furthermore, few of these organizations have dedicated teams to concentrate specifically on children and those who do often feel inadequately trained (Vesel & Beveridge, 2018). As dismal as this might sound, proficient care is increased when more providers engage in the process including those who mainly practice adult medicine.

Feeling inadequately prepared to begin the process no longer should impose a barrier. Training programs are now available to make the learning experience more streamlined and easier to deliver. For instance, two large training programs now exist for pediatric end-of-life care. Nurses may gain further knowledge through the End-of-Life Nursing Education Consortium (ELNEC): [www.aacnnursing.org/elnec](http://www.aacnnursing.org/elnec). Other providers may choose to learn from the Education in Palliative and EOL Pediatrics program while also attending its annual conference: [www.bioethics.northwestern.edu/programs/epec/curricula/pediatrics.html](http://www.bioethics.northwestern.edu/programs/epec/curricula/pediatrics.html). Furthermore, the National Hospice and Palliative Care Organization (NHPCO) provides additional information and resources to help this endeavor succeed: [www.nhpco.org/pediatrics/](http://www.nhpco.org/pediatrics/).

These programs are instrumental and can make a difference. One two-day training program that specifically aims to teach adult providers how to provide services for children is encouraged by the results received after the program is complete. Vesel and Beveridge note that, "In just two days, participants in our course felt generally better prepared to care for pediatric patients and also improved their knowledge of, skills with, and attitudes toward carrying for children" (p.6): [www.jpmsjournal.com/article/S0885-3924\(18\)30179-9/fulltext](http://www.jpmsjournal.com/article/S0885-3924(18)30179-9/fulltext). The education piece is now certainly available, and children await more providers to take the initiative to learn and then provide the care that is deserved.

The power to help alleviate patient burden through compassionate intervention cannot be overstated. Patients note a decrease in symptoms, obtain improved quality of life, and demonstrate higher quality-of-care ratings (Malenfant et al., 2022). One need only to provide a warm hand and gentle touch to make this happen. End-of-life care allows providers the opportunity to act more compassionately through real intervention in a world that often expects quicker turnaround visits in the office space. More importantly, providers are given the opportunity to return to the past so-to-speak when treating patients at their final stages of life. Home visits that were once included in the daily provider schedules in the past, continue to serve a vital role in the palliative world. Visiting a sick child at his or her home not only allows for medical care to be given, but also promotes a deeper relationship to develop with both the child and the involved family. What a pleasure it is for anyone to receive the blessings that flow from these visits and a sense of actually doing "something" is achievable. Past providers once took the initiative to do it and the time is right for a present understanding to begin once more.

Thank you for your consideration and effort to help support the wonderful children that need your help. You CAN do this. Assistance is available to help you achieve success and the children will make you feel like a champion while doing so.

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# What Do You Do When You Don't Know What to Do? Caring for Seriously-Ill Children

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A 2020 National Hospice and Palliative Care Organization palliative care needs assessment survey revealed 66 of 225 respondents were caring for children and, of those, 35 reported dedicated staff with pediatric expertise.<sup>1</sup> We can safely surmise there is not one robust pediatric program in every state and that rural or resource-barren areas may have limited staff with pediatric expertise. Many programs and providers are challenged when caring for children due to insufficient resources, lack of pediatric trained staff, and the need for pediatric continuing education specific to child development, pharmacological management, and pain assessment. Children are not small adults and because of this pharmacokinetics differ greatly and neurodevelopment may not be complete. When a provider without pediatric expertise finds themselves caring for a patient, what should they do?

Knowing available resources is critical. Start local. Identify pediatric experts in your community, like pediatricians and subspecialists who care for children with medical complexities, and build relationships centered around mutual patients. Consider shadowing inpatient or outpatient teams at a nearby children's hospital to familiarize yourself with resources and referral sources. This in-person observation and refresher of pain evaluation and management, age-appropriate care delivery for the developing child, and dosing for pain and symptom management needs can provide familiarity and comfort when caring for seriously ill children. In addition to establishing relationships with other providers in your community, build a library of expert resources for yourself. Pediatric specific references, like *The Harriet Lane Handbook*,<sup>2</sup> provide age and developmental considerations and recommendations for many common pediatric scenarios.

In addition to differences in care delivery, language and vocabulary differ greatly with children and their families when addressing pain, symptom, and end-of-life care. Communication is our most valuable and challenging procedure in hospice and palliative medicine. There are many courses that offer pediatric specific education. Both End-of-Life Nursing Education Consortium (ELNEC)<sup>3</sup> and Education in Palliative and End-of-Life Care (EPEC) offer pediatric courses focused on multidisciplinary care for seriously ill children. Many key topics are covered including communication and advanced pain and symptom management. VitalTalk, a non-profit organization, offers serious illness communication and train-the-

trainer courses for those caring for seriously ill patients. The Center to Advance Palliative Care (CAPC) has many great resources including self-paced modules.

There are many free or low-cost options to improve your comfort with and exposure to seriously ill children. Engage the greater pediatric hospice and palliative care community by joining listservs. The American Academy of Pediatrics and the American Academy of Hospice and Palliative Medicine have pediatric palliative and hospice care listservs that offer opportunities for networking and learning.

Seriously ill children are ideally best served by teams of pediatric experts. When this is not possible, establish and invest in a core team with access to community experts. Many of the mentioned resources offer train-the-trainer options affording teams the opportunity to share knowledge, continue training, and improve staff comfort.

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# My Recipe – Not the Only Recipe

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Child Life Specialists are sometimes told their jobs are easy because they get to play all day. While partially true, a certain skill set is required to work effectively with children and teens. Over the past 28 years, I have worked in three hospitals, one pediatric palliative care home, and two hospice agencies. Each place had their own culture and style, but my way of practicing as a child life specialist remained relatively constant. The information in this article is based on my experience and values and is transferrable to all settings and disciplines.

## First Impressions

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Whether you are a nurse, a physician, a psychosocial provider, or a member of any other discipline that works with children and teens, a typical day probably finds you without much time to look past the medical data in your patient's chart.

What can you do when you meet a pediatric patient for the first time? I am offering you my recipe, but every recipe includes more than the selected ingredients. I am not asking you to have a "personality transplant," but I am inviting you to explore the ways you communicate with your patients and their families. My first suggestion is to bring your best genuine self into the room. Don't try to be someone you're not. For example, if you are not a naturally funny person, don't try to be one. Most kids can easily identify what's real and what is not. Do your patients need to like you? Not really, but they do need to trust you, and this is a good place to start.

Building a trusting relationship begins the moment you walk in the door. First impressions matter, and it's important to remember that you are not the only one doing an assessment. Take your time. Read the room. Think about how you want to introduce yourself. I always try to make a non-threatening connection. After introducing yourself you might want to ask, "*What do you want me to know about you?*". If you receive a blank stare or a shoulder shrug, ask an easy question – "*What's your favorite \_\_\_?*" Tell them yours. This approach takes very little time and can be quite effective in establishing a trusting relationship.

Knowing your patient's developmental age is not enough. Children and teens are not theories and cannot be placed neatly into a box. Temperament and previous healthcare experiences also play an important role in how people of all ages relate and cope during stressful times. You probably will not find this information in a specific place in the chart. Consider working with your IT person to create a separate section in the electronic medical record for all this useful information.

## Direct vs. Indirect Communication

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Always assume your patients are listening even if they are immersed in play or sleeping. Because younger children are often unable to put together the totality of an overheard conversation, they create a construct that makes sense to them. Here is an example.

*The physician was talking with the mother of a 5 y.o. boy in the doorway of his hospital room explaining fluid accumulation in the child's abdomen. The child was seemingly 100% engaged in a video game. The physician used the word 'edema' multiple times. Soon afterwards, the child stopped talking and going to the playroom. He wouldn't tell anyone what was wrong. I worked with the child's mother to decipher what might have happened. On the 3rd day, this frightened child told me that he had a demon in his belly.*

Before you begin a conversation with a parent/caregiver, check in with your patients. Do they want to listen? If yes, use developmentally appropriate language and try to directly talk to them. If no, move the conversation elsewhere. Try to stay within eyesight. Usually outside the door is enough.

## Language

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Like most complex systems, healthcare uses acronyms and words that are not commonly understood. Use concrete medical terms but provide clarification. A CT/CAT scan, for example, might easily roll off your lips but to a child unfamiliar with medical terminology, those words can be confusing. Your patient might be wondering "What is a scan, and why do you want my cat to have one?" Another phrase that is subject to misunderstanding is "flush your IV" (Are you flushing ivy down the toilet?). Maybe funny to you, but not to your patients who are just trying to make sense of all that is happening to them in an unfamiliar environment.

## The Truth, the Whole Truth and ...

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Not exactly. What you say to your patients should be honest and delivered at a level they will understand. Some children/teens are information seekers and ask many questions. It's okay to say, "I don't know" when you don't have an answer. Listen to the content and feeling expressed. Don't dodge or answer the question indirectly. Try to use reflective listening especially when you are asked a challenging question. Clarifying the question gives you time to pause, to think about how you will respond in a way that does not overwhelm your patient. This approach also provides you with an opportunity to identify misconceptions.

## Interpreters

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It is not enough to ask caregivers if they need or want an interpreter. If questions are not being asked or are mostly answered with simple yes/no responses, it might be because the caregiver is uncomfortable speaking English. Avoid asking siblings, relatives, and non-skilled staff to interpret. Unless you are fluent in the language, please wait for a trained interpreter as this will save time and misunderstanding in the long run.

## Daffodil Analogy

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I will close with this. My first internship with a rehab team taught me that everyone has an equal place at the table. Several years into my practice an oncology nursing colleague and I discussed what that meant in practice. We came up with the image of a daffodil. First, there is the patient—the center of the flower. The next layer is the family. This primary supportive unit is surrounded by petals that represent not only physicians, nurses, social workers, spiritual care providers, and child life specialists, but also ward clerks, housekeepers, and interpreters. Families notice how we relate to one another. I hope you agree that, regardless of position, everyone on the patient's team serves an equally vital role.

# Key Considerations When Working with Parents of Children with Serious Medical Conditions

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Working with seriously-ill children and their families, while very meaningful, can also bring about a sense of apprehension for clinicians who have primarily trained and worked with adults. It is important to acknowledge that some clinicians have chosen a career where they would not encounter pediatric patients, because it can be difficult and sad to see very ill children and because of a high level of empathy for their parents. Others may have merely preferred training in adult care. A noteworthy difference within pediatrics is the presentation of a wider range of serious disease types compared with those of adults with serious illness, often with less clear prognoses and life expectancies. Further, pediatric patients are eligible for concurrent care, although some states and some private payers do not adhere to this. Concurrent care means that, unlike with adult hospice, pediatric hospice allows children to continue with all potentially curative interventions and treatments while also receiving the support of the whole hospice team for the child and family.

## The Parent as Caregiver

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Hospice and palliative care clinicians are typically well versed in developing collaborative relationships with caregivers who are supporting the patient emotionally and/or practically. While there are certainly commonalities in the emotional landscape for families where the patient is an adult and where the patient is a child, there are some important considerations specific to pediatric patients that can help promote clinical confidence and help avoid pitfalls in the relationship with the family. In the case of seriously-ill children and youth, parents are typically the caregiver (though not always), and their emotional and practical burden is substantial. Underlying the experience is existential distress arising from the devastating, and seemingly illogical, reality that their child's death may precede their own. Also, while parents describe great meaning in their role as a caregiver, this is typically accompanied by a high level of caregiving burden and distress related to navigating the medical system, tending to the needs of siblings and partners, maintaining paid work, facing financial concerns, coping with changes in social support, and more.

When a child is sick, the entire family is affected. Thus, a central tenet of working with seriously-ill children is *that care is in essence being provided to the entire family*. Beginning at diagnosis, parents (or other primary caregivers) will experience a range of emotions that may include fear, anger, and/or sadness. It can be helpful to give these feelings a name and reassure caregivers that these feelings are normal and part of *anticipatory* grief. Anticipatory



grief involves grappling with and grieving the losses now of what is expected, or some of the hopes and dreams for the child long before the future, whatever that will be, unfolds. This grief can take up a lot of room in parents' minds and hearts.

Parents want to be strong advocates for their child and make the best decisions that they can, which includes those that are well-informed and in line with their goals and values—both of which can shift over time. They should be acknowledged as the experts in understanding their child's needs, goals for their child's care, and knowing what is best for their family. There is often a spoken or unspoken fear of regret, which clinicians can help mitigate by engaging parents in shared decision-making; making recommendations based on their medical knowledge and knowledge of the family and child; and, when possible, allowing parents adequate time to make decisions.

## Connection

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Central to all of this is the importance of building a trusting and honest relationship between the caregivers and the clinicians. Very early interactions can set the path for a strong connection. In many cases, by the time palliative care or hospice is introduced, parents have become adept in navigating the healthcare system and conversations with their child's familiar multidisciplinary medical team. Thus, the introduction of a new team, particularly when done because of a change in their child's status, can cause parents to feel uneasy. Clinicians can support this transition and foster connection by inviting the caregivers to introduce their child. Clinicians should call the child by name and, if appropriate, make direct contact with the child themselves. Connection is also fostered by being curious about the child's interests and preferences and the family's non-medical life. This helps the child and family feel seen and respected beyond the diagnosis. Also, asking about the child's typical day can provide new appreciation for the complex caregiving (scheduling, medication management, therapies, interrupted sleep, etc.) that is needed to support a child in the home. Asking to see photos or short videos of how the child presents on a "good" day or during a "bad" episode can allow clinicians to identify solutions to some issues and connect to the personhood of the child, both of which are priorities for parents.

## Communicating with the Parents

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As the relationship unfolds and conversation shifts to the needs of the child, very often clinicians describe tensions in the communication or reactions from the parents that may appear incongruent with the circumstances. It may be the case that how the parent is presenting is not what is really going on with them; emotion, or lack thereof, from the parent is an opportunity for the clinician to pause and consider what it might really be and then, perhaps, asking more questions to get at the parents' true concern or status.

Consider the following examples of parents' presentation:

What it seems like	What it could be...
Parent seems angry	Parent is scared, grieving
Understands everything well	Totally overwhelmed and doesn't know how to ask for help or what to ask
Keeps asking for more interventions	Fears that clinicians have not considered all options and/or will not keep looking for interventions that may benefit the child

Clinicians can better understand parents' perspective by scaffolding conversations that elicit their feedback through the use of gentle, open-ended or reflective questions such as:

*Would you help me understand what you mean by ...*

*It sounds like you feel that you have no control ...*

*Please tell me if I am understanding you correctly...*

Clinicians can enhance their relationship with parents by validating their feelings and using empathic statements or simply being present and listening. You might begin with: I'd like to talk about how your child is doing from both of our perspectives, I wonder if we can make a time to talk together.

*This feels so difficult...*

*I am so sorry this is happening*

*This must be overwhelming.*

## The Critical Role of Hope

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frequently cited concern by clinicians is the perception that the parent is in "denial." For some parents this can be a helpful coping mechanism for getting through each day. It may seem that the parent is avoiding making decisions regarding issues that clinicians feel are approaching imminently. Caregivers may decline a meeting to talk about the "big picture" or may speak about future plans for the child. In these circumstances it is common, and natural, for clinicians to feel frustrated or confused. They may worry about a child's suffering or a parent later regretting some of the care decisions or their indecision. However, it is very rare that a parent is truly in denial or is unaware of the gravity of the situation. What is common, however, is parents' innate need to maintain hope alongside a desire for honesty and clear language about their child's condition. Clinicians have an obligation to maintain hope and can do so by aligning with the parents while also communicating concerns about what they are seeing: for example, "I am also hoping that they will have another birthday, be cured, live longer. I am also concerned that their condition is not improving." Usually, over time, caregivers' goals will shift to placing the child's comfort and relief of suffering above all else through focused symptom management and providing a safe and loving presence to their child.

## Learn More

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To learn more about the experience of parent caregivers, please visit Courageous Parents Network and view more than 600 videos, podcast interviews, and blog posts of parents who speak to all aspects of caregiving, and provide a direct and intimate view into navigating their social and emotional experience. Join CPN to gain access to the Clinician Portal, which contains additional materials for self-education and training. For more information, please read out directly to Chrissy Salley, Ph.D., Director of Clinician Outreach & Engagement at [Chrissy@courageousparentsnetwork.org](mailto:Chrissy@courageousparentsnetwork.org).

# POLST or MOLST, Advanced Care Planning, And Pediatrics

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Physician's Orders for Life-Sustaining Treatment (POLST) or Medical Orders for Life-Sustaining Treatment (MOLST) are physician's orders that give patients more control over their care by specifying the types of medical treatment they want to receive if they become seriously ill. These documents are often referred to as "portable medical orders." For this article, we will use the acronym POLST, but MOLST/POLST refers to the same type of document. What the form is called is state-directed. To find your state's form, visit the National POLST website at <https://polst.org/>

POLST is a useful tool that can encourage communication between healthcare providers and patients/families. The POLST also enables patients and families to make more informed decisions and clearly communicate these decisions to healthcare providers. Using POLST as a tool to determine goals of care and advance care planning can help ensure that patient wishes are honored. POLST, as a physician's order, is recognized throughout medical systems; it is portable, can transfer from one care setting to another, and is standardized for the entire state where it is being used. One important note: POLST helps inform the healthcare team when a child is admitted; however, the inpatient care team should confirm the goals of care and wishes documented, and write orders for the inpatient chart to cover the inpatient stay. In some states the POLST is a legal order that can be used within the inpatient setting. It is important to know the regulations in your particular state.

Although anyone can have a POLST, the form is designed for, and may be regulated by state legislation, for use with individuals who have a chronic progressive illness, or a life-limiting health condition, or are considered medically fragile. There are no age specifications, and the POLST can be used for both pediatric and adult patients. A helpful tool for determining who would benefit from use of POLST is the question, "Would you be surprised if this patient died within the next year." This question reflects that the determination of who is appropriate for POLST is an art, not a science.

Some key points regarding the use of POLST:

- The use of POLST is voluntary
- The same form is used throughout the individual state
- Honoring the form is mandated; it is a legal physician's order when completed as directed
  - An exception is when the wishes documented on the POLST are contrary to generally accepted healthcare standards or call for medically ineffective treatment
- Following the portable medical orders provides immunity from civil or criminal liability
- POLST should be reviewed with the patient and family regularly, especially after any changes in the patient's condition or during all hospitalizations

Many states have created or are creating POLST registries for easy access to these forms for all healthcare providers. More information on the state registries can be accessed through the map on the National POLST website, <https://polst.org/programs-in-your-state/>

## POLST and the Advance Healthcare Directive (AHCD)

The legal Advance Health Care Directives are designed for adults 18 years and older. Some young adults receiving care from pediatric teams may have Advanced Health Care Directives. However, most pediatric patients are younger than 18. Of note, even with the use of Advance Health Care Directives, the additional use of the POLST may enable a more nuanced approach to goals of care and better identify what treatments the patient and family do or do not want. The POLST form travels with the patients across all care settings and clearly states what types of care is wanted and what is not.

POLST	AHCD
For seriously ill / medically fragile, at any age	For anyone 18 years and older
Specific orders for <b>current</b> treatment	General instructions for <b>future</b> treatment
Can be signed by decision-maker / or patient 18 years and older	Appoints legal decision-maker

The POLST does not replace AHCDs but complements them. POLST must be completed with a healthcare provider, including a physician, nurse, social worker, and chaplain, although each should be trained in using the POLST. All POLST forms must be signed by the patient’s physician/nurse practitioner or, in some states, physician’s assistant, to be a legal medical order. The POLST is recommended to be completed following diagnosis of serious illness at any age. AHCDs have no universal form, are focused on the future, and can only be completed if 18 or older. A physician’s signature is not required as it is not a physician’s order but a legal form to document your wishes should something happen in the future, including designating who should make decisions for you if you can no longer decide for yourself.

There is also a “Pre-Hospital DNR (Do Not Resuscitate) form in some states. The POLST and Pre-Hospital DNR are both physician orders; both address “Do Not Resuscitate” if a patient’s heart is not beating or the patient is not breathing. Both are for the medically fragile or those with serious illness. The Pre-Hospital DNR is only used if the patient/family chooses not to resuscitate; it only applies to resuscitation and can only be honored outside the hospital. Its primary goal is to communicate the DNR wish to emergency personnel. In some states, the Pre-Hospital DNR form has been retired and the POLST form adopted in its place. For this reason, it is important to know what forms are legal and used in your state. POLST forms and specific guidelines/requirements can be found on each state programs’ websites.

## Advantages of the POLST in Pediatrics

One of the main benefits of using the POLST is it can specify the range of treatments that patients do or do not want. The POLST allows for choosing resuscitation or to saying no to resuscitation. The POLST also allows for decisions about other medical treatments such as artificial nutrition. It can be an important tool for assisting the pediatric team in goals of care discussions, reviewing prognosis, and making clinical recommendations. As a tool, it can be effective in helping with these difficult conversations and documenting the wishes of the patient and family. It can be used to revisit goals of care when there a shift in baseline and progression of the disease, and, subsequently, it can be adjusted to reflect any changes in interventions desired by the patient and family.

Why is this important? We know that the population of children with complex medical conditions is increasing, and many children often outlive their prognosis (US Dept of Health and Human Services, 2021). We also know that these children's trajectories are often unclear, with lots of ups and downs, often with frequent hospitalizations.

### **CASE STUDY:** *(this case is a compilation and not representative of any one patient/family)*

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Selena is 15 years old with severe cerebral palsy and developmental delay. She is non-mobile and non-verbal, but communicates with smiles and gestures. Over the last two years, she has had repeated hospitalizations for pneumonia. Selena lives with her parents and two younger healthy siblings. She has been home for about a week after her last hospitalization for a respiratory infection. She is now oxygen dependent.

Her parents have an unexpected need to attend a special event, and Selena's grandmother babysits for the evening. Grandmother does not speak English. Selena starts having difficulty breathing in the evening, and her lips turn blue. Grandmother calls 911, and Selena is transported to the ER, where she is intubated and transferred to the ICU.

Unfortunately, due to family dynamics, Grandmother did not know that during the last hospitalization, Selena's parents learned that her lung capacity was less than 25% and another infection would likely result in her death. Her parents decided to transfer her to hospice care with no more hospitalizations. They had made the difficult decision not to resuscitate if Selena stopped breathing again. The parents had not yet been able to inform their family of their decision or the newest prognosis.

There was no documentation of the DNR, and Selena was over-treated against the parent's wishes, which caused unnecessary pain and suffering. There was a lack of communication within the family, the EMS system, and healthcare providers. A family meeting before discharge may have helped mitigate this outcome, and completing a POLST would have guided the emergency responders on what care to provide Selena.

The POLST is a valuable tool for care teams working with pediatric patients. It is a comprehensive form that can be used to engage families in difficult conversations about goals of care. The key to exploring goals of care with patients and families requires understanding the patient's medical condition and what to expect as their disease progresses. If there are questions, they should be referred to the patient's physician. It often is more effective with a team approach to work with the family to clarify goals and options with at least one medically trained participant and one good listener/observer. By utilizing this approach, families will be better able to make informed decisions about the medical care of their child. The POLST is honored across all healthcare settings, such as clinics, home, EMS, rehab, etc., and will help make sure that the treatments that pediatric patients receive are those that align with their values, beliefs, and goals of care.

# Adapting an Adult Hospice Inpatient Unit to Meet the Needs of Pediatric Patients

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Treasure Coast Hospice, a non-profit, community-based hospice agency, has served pediatric patients since 2014 through their specialized pediatric program called Little Treasures. Since its inception, a continued challenge of the program was utilizing the inpatient unit (IPU) for respite, acute pain management, and end-of-life care for its pediatric patients. To attend to the need of using the IPU for the pediatric patients, the Little Treasures team conducted several focus groups with the IPU managers and nursing staff. The purpose of the focus groups was to identify chief concerns that prohibited the ease of access to the IPU for pediatric patients, to brainstorm ways to address and overcome those concerns, and to ensure the high-quality care of pediatric patients during their stay at the IPU. From the data collected during the focus groups, three key themes emerged: (1) operational needs; (2) hesitancy of adult-focused nurses to care for pediatric patients; and (3) the emotional distress on staff that accompanies caring for pediatric patients at end-of-life.

## Operational Needs

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The operational concerns identified by the IPU staff focused around ensuring the safety of the pediatric patient during their stay at the IPU. The need of pediatric equipment and the ability to adequately monitor the patients were each noted by staff as challenges to adapting an adult-centric IPU to pediatric patients. Another main concern verbalized by the staff was knowing how to navigate the care of the pediatric patients who would come in for respite care but who were actively receiving concurrent care. The key aspect of this concern focused around the pediatric patients who remained full code.

## Hesitancy of Adult-Focused Nurses to Care for Pediatric Patients

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Several nurses verbalized that they had limited experience with pediatric patients, especially in hospice care. They were apprehensive about caring for a pediatric patient and how to transfer their skills to attend to the child's physical, developmental, and emotional needs. They also cited that they were worried about the interactions with the family system, especially if the primary caregivers or parents were having a difficult time coping with their child's illness and prognosis. They were unsure of the language to use and questioned their abilities to adequately support parents and siblings in heightened emotional states.



## Emotional Distress

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Emotional distress that could accompany caring for a child with a life-limiting condition was another consideration identified by the focus groups. Issues of transference and countertransference were apparent. For example, one nurse reported that she has children of a young age and that it would be difficult for her to bear witness to a child dying and the family experiencing the death of a child as it would be “too close to home.” Others reported they were unsure of how they would emotionally handle the experience of working with pediatric patients at end-of-life and expressed fear surrounding the unknown.

## Strategies Implemented to Adapt the IPU for Pediatric Patients

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Several strategies were implemented to address the concerns identified by the IPU staff. First of all, it was apparent that obtaining pediatric-specific equipment and converting the rooms to be more pediatric-friendly was paramount to easing staff’s concerns, as well as providing a more welcoming space for the pediatric patients and their families. Funding was secured through community partnerships and the agency’s foundation to buy pediatric equipment. Equipment that was purchased included a refurbished medical-grade crib, a video baby monitor for the nurse’s station, and a portable cart to store pediatric medical supplies. Additionally, several child/teen-themed bedding and decorations were purchased to convert the adult rooms to a child-friendly room. The equipment is stored at an off-site storage unit and brought into the room at the IPU as needed. Prior to the pediatric patient arriving at the IPU, Little Treasures team members or volunteers go in and decorate the room to make it a warm and comforting space for the child and family. A care basket is also made for the room that is specific to the family. The care basket may include snacks, games for the patient or siblings, movies, and, if appropriate, items to create legacy projects.

Specific admission protocols for the pediatric patient were also developed. A complex case conference prior to the pediatric admission to the IPU is one protocol that was added. The complex case conference consists of the IPU manager(s), the medical director, and the Little Treasure team (program director, RN, social worker, chaplain, music therapist, ARNP, and the contracted pediatrician). The goal of the meeting is to review the patient’s history, medical needs, and medications, and to discuss any psychosocial considerations. During this meeting, any potential nursing challenges are identified and strategies to mitigate those challenges (i.e., specific education, increased nursing support, engaging a volunteer to sit with the patient) are discussed. The actions to take when a patient is full code are also defined for the nursing staff.

When the pediatric patient arrives at the IPU, the nurse and social worker of the Little Treasures team are present to greet the family, make introductions to the staff, and assist with settling the patient into the room. The Little Treasures nurse and social worker round each day at the IPU throughout the stay of the pediatric patient. Additionally, if the music therapist and chaplain are involved with the family, they increase their frequencies. The purpose of the rounding and increased frequencies of the interdisciplinary team is two-fold. First, it is to ensure the continuity of care for the patient and family. We have found that having the team that they are most comfortable with helps to ease any of their fears of being at the IPU. If difficult conversations need to be had, it is the pediatric team who is guiding those conversations with the family. Secondly, it is to check in with the staff at the IPU and to support them in their care of the patient. In situations where the patient is transitioning to end-of-life, the social worker of the team will offer space to the IPU nurses to process their experience and add a level of additional emotional support to them.

To address the hesitancy and worry of the IPU staff in caring for a pediatric patient, the hospice agency brought in a specialized training conducted by Courageous Parents Network. The training focused on acknowledging the emotions that accompany working with pediatric families and language to use. Additionally, a pediatric booth was added to the annual nursing skills fair to promote nursing competency around the most common pediatric symptoms and needs.

The implementation of the focus groups assisted the agency to identify challenges of using the IPU for pediatric patients and created an avenue to problem-solve ways to overcome those barriers and care for pediatric patients in the IPU. After each pediatric admission and stay at the IPU, the Little Treasures team and IPU management meet to review the case and identify ways to improve processes to ensure the best standards of care for the child and their family. The continued collaboration and willingness of all professionals involved to learn is paramount to this endeavor and has allowed Treasure Coast Hospice to successfully utilize the IPU to meet the unique needs of their pediatric patients and families.

# A Person is a Person No Matter How Small

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When people hear the word “hospice,” they usually think of end-of-life care for adults, particularly the elderly. Few consider hospice or palliative care for the pediatric population. According to the *2023 Pediatric Facts and Figures* report released by the National Hospice and Palliative Care Organization, there are very few pediatric-specific hospices and palliative care teams in the country, and the number of board-certified pediatric clinicians on adult teams is low. Consequently, many adult providers face the challenge of providing child and family-centered end-of-life care. While these clinicians are highly skilled in caring for their adult patients, they require a specific skill set and knowledge base to care for pediatric patients.

At Hospice of the Western Reserve (HWR), most patients cared for are adults. Fortunately, HWR is also committed to providing hospice and palliative care to pediatric patients and families. While the care provided to pediatric patients primarily occurs in the patient’s home, there are times when a pediatric patient may benefit from care at one of our hospice houses. Caring for a pediatric patient as an adult nurse in a hospice house setting can evoke a range of complex emotions. Support for staff who primarily care for adult patients is especially important when they are faced with caring for a pediatric patient.

To increase support and the comfort level for staff, our pediatric team meets with them before admitting a pediatric patient. The child’s primary nurse provides a detailed clinical history, while the social worker trains staff on developmental responses, age-appropriate interests, and pertinent psychosocial factors related to the admission.

After talking with the parents or caregivers to learn more about their child, the pediatric team creates an “All About Me” poster that is displayed above the child’s crib or bed at the hospice house. This poster highlights various likes and dislikes, and provides insights to the staff on how to best care for them. We encourage families to bring in special items that their child likes to help personalize their room. Families are invited to stay with their child at the hospice house, but there are occasions when they are unable to do so. The “All About Me” poster gives the child a voice and fosters connection with the caregivers at the hospice house. Additionally, we strive to ensure privacy by using a partition-type divider near the door.

Since many adult providers lack significant pediatric experience, it is easy for boundaries to become blurred and ethical or moral dilemmas to arise. This situation presents a valuable opportunity for collaboration between pediatric and adult providers and for training on the delicate balance of child-centered care, maintaining boundaries, and respecting care decisions. At HWR, our pediatric team provides training on available resources that

can be accessed to meet a patient's identified needs without utilizing personal resources. This helps reduce boundary violations while assuring adult team members that the child's needs are being met.

The presence of a pediatric patient alters an adult care provider's daily workflow. Due to the unique physical, psychosocial, and spiritual care needs in pediatrics, it is crucial for team members to remember the importance of confidentiality. While collaboration and peer support are critical in effectively caring for a pediatric patient, it is essential to remember that discussions about the child and their family should not be the main topic of conversation throughout the hospice house or with other curious families in an environment primarily designed for the needs of adult patients.

The pediatric team continues to support the child during their stay at the hospice house, making weekly visits, or more if necessary. Ongoing support and formal and informal education are provided based on emerging needs. Caring for a pediatric patient can be emotionally intense and evoke feelings of sadness, grief, or helplessness. This is particularly heightened if the child dies during their admission to hospice house. Our team offers debriefing sessions for the staff to share their feelings related to caring for the child. Staff members can recall special memories from their time providing care and express the emotions it brings up for them.

Pediatric team members also have a unique opportunity to provide training and support for their adult colleagues regarding care decisions. Ethical or moral concerns often arise due to countertransference and the fact that the death of a child defies the natural order. Providing opportunities for processing concerns, holding care conferences, and seeking ethics consults ensures that everyone's needs and concerns are addressed in real-time. These situations also serve as valuable training moments.

During a patient's stay at the hospice house, the pediatric team is present to provide support to the patient's siblings and peers as well. Prior to the arrival of a sibling or peer, the pediatric social worker collaborates with the patient's family to prepare the child for the sensory input they may experience when walking through hospice house. Memory making, emotional support, and anticipatory grief support are provided through various therapeutic interventions facilitated by the pediatric social worker, spiritual care coordinator, and expressive therapists.

In our efforts to foster a nurturing environment and create a supportive, resilient team that feels comfortable caring for future pediatric patients at the hospice house, our pediatric team recognizes the need to prioritize the emotional well-being of staff members providing care to pediatric patients. The pediatric team members acknowledge and address the range of emotions the staff may experience, providing them with a safe space to share their thoughts and feelings.

# Caring for Pediatric Hospice Patients From the Perspective of Adult Hospice Care Practitioners

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There are several opportunities for hospice workers to seek and obtain education regarding hospice and palliative care through several local and national organizations and some at the university level. However, when reviewing curriculum in most nursing and medical programs, it remains far lacking in content and more important in active dialogue. Most practitioners remain uncomfortable in discussing topics related to end of life resulting in 'missed moments' between the practitioner, patient, and family.

Those working in the hospice and palliative care field have received often inadequate formal and informal education on how to address these often-difficult discussions. This has left many practitioners who work in hospice and palliative care often uncomfortable to have these very intimate conversations with their patients. Surprisingly, a great percentage of hospice and palliative care providers have not had these very conversations with their own families, and many do not have an Advance Directive.

So how do we break this barrier? This has been asked, discussed, and studied over the years. And we still see many obstacles in providing access to care such as myths around hospice and palliative care, beginning those difficult discussions, and locating providers. Since most of our hospice and healthcare organizations work with the adult population, working with families and patients in pediatric population only adds another barrier to access as there are limited organizations that provide this care to children across the nation. When speaking about children in terms of end-of-life care, many respond, even those working with children in healthcare, that children are not meant to die or need hospice and palliative care services. The two concepts together—children and end-of-life care—just aren't natural. In pediatrics, the focus is primarily on curative treatments even in the presence of serious illnesses.

So where is the disconnect? Is it within the current medical module of acute care principles of pediatric providers, like adult providers who see death as a failure of the medical system? We do know that healthcare providers and families have more misunderstandings and lack of knowledge. In addition, most pediatric hospice and palliative care programs only exist in concentrated areas of the United States ([State of the Service: Pediatric Palliative and Hospice Community-Based Service Coverage in the United States.](#)). Even after many decades this holds to still be true. We have always known that members of the pediatric population are not little adults and require a whole different approach to healthcare. The same is required for those with serious illnesses who could benefit from hospice and palliative care services. So how do we bridge this gap?

Most hospitals also are not prepared to take on providing pediatric hospice and palliative care options for these families. This leaves free-standing hospice homes for children—which are very few across the country. Even pediatric hospitals that may have comprehensive palliative care services and provide compassionate care, rely on local community hospice services when available. This leads us back to a lack of access to quality pediatric programs.

Building free standing programs for pediatrics in hospice and palliative care is not feasible in most cases due to operational costs, resources, regulations, and reimbursement. Even if they do proceed, without a huge pool of

pediatric-trained clinicians, it is not possible for most pediatric teams to cover the care needs of children and their families 24/7. Most programs are not large enough to support a large pediatric trained staff.

One would suggest that the best option would be to implement a pediatric hospice and palliative care program within an organization caring for adults. However, this is not always pursued for the same reasons such as financial feasibility, regulations, and trained pediatric staff. In addition, adult hospice and pediatric clinical staff are not equipped to care for children who are dying and their families. Nor are they equipped to be advocates and assist them in navigating within the medical model. However, a few hospices are taking steps to incorporate pediatric care. During the initial stages of program development and seeking out pediatric experts (medical, nursing, social work, and chaplains), they are often faced with training adult providers to support. As a result, those caring for adult hospice and palliative population are branching out to train their adult staff to care for pediatrics. How do you even begin this daunting process?

There are key points that are extremely important to address when building a pediatric program within an adult hospice organization that I have learned firsthand after managing two pediatric programs (one I co-developed with Liz Sumner from the ground up) within not-for-profit hospices. Caring for children and their families is not the same as caring for adults, mostly elderly, at their end of life who are facing death. There are also differences in reimbursement, availability of services, staffing levels, and the focus of difficult decisions. So how do you prepare your staff? First, is realizing those differences. It goes far beyond of providing didactic training and even practicum experience. To begin, you need to address the emotional component and how the staff are feeling about caring for children and their families. Remember even for those comfortable working in hospice and palliative care does not mean that they will be able to adjust to working with children. Again, "children are not supposed to die."

While it is important in creating a quality pediatric palliative care curriculum or using an established program, you will need to address their fears and concerns. This should be a first step after deciding to go forward with a pediatric program. When we initially announced at the hospice I worked at that we were moving forward with a pediatric program, everyone was excited at first until the reality of what their role might be in interacting with this population. Then the concerns, questions, and even resistance kicked in. What we decided to do was to develop an introduction module for all staff to attend regardless of their role in the agency. The module provided an overview of pediatric hospice and palliative care and our plan to develop a team of pediatric clinicians. However, we were clear that others in the agency (office and field staff) would be needed to participate for our program to be successful. Providing time to review all their concerns before beginning a program will ensure a higher level of adaptability and success.

In this introduction module, I have found it to be very successful to address any concerns in a safe environment. At the beginning of the session, I had the participants take post-it pads and write a concern on a post-it note. I encourage them to write as many as they need to. I then put them all 'on the wall' by category. The categories probably would not surprise you and included medications, equipment, supplies, procedures, psychosocial issues, emotional impact, saying or doing the wrong thing, handling a change of condition, the POLST, DNR, AND, providing CPR, concurrent care, and what to do at the time of death. After I finished the presentation and overview of pediatric /perinatal hospice and palliative care, we then address the post-it notes one by one. The results of this exercise proved to be very rich for everyone. We allowed as much time as needed to discuss some very deep-seated fears and concerns. With each one, I asked the participant, 'what do you do now?' For example: What if you do not know a medication and are doing a procedure, working with strange equipment? What if you get too emotional now? What do you do with a discussion about whether to go the hospital, come off hospice, handling the time of death, etc. In most cases, the participants could state with confidence and knowledge of what they would do with an adult patient. One by one we discussed what they would now do with a pediatric patient. What did we find? In most cases, we heard the same answers. Now there were some nuisances in pediatric care when it came to consenting or assenting, concurrent care, going to the hospital and current treatments. In almost all cases, the participants began to see that while they may still be uncomfortable, they do have the innate clinical skills, critical thinking skills and knowledge to care for pediatric patients.

The most common worry and hurdle turned out to be not knowing if they could handle their own emotions. It is important to allow more time for this, not just in the beginning but going forward. Staff are concerned of course about doing the wrong thing, especially when it comes to an infant or child, and they need reassurances that someone will be there to consult before and during the visit, and be able to debrief after their visit. I found this to be critical in staff feeling successful in caring for children. In some cases, because they had such a positive experience, it sparked an interest in staff to become part of the pediatric team or be the resource/point person in their department (office, triage). Others, as expected, continued to be cautious and uncomfortable. However, making sure that they knew what their resources are during a busy day, after hours, and on weekends is key. It is imperative that there is at least one person who is an expert in pediatric care to be available by phone 24/7 to provide support.

After the providing the introduction module, the next step would be providing more extensive classes in pediatric hospice and palliative care either developed by the pediatric team or using a program that already has been developed. I have done both. Using our own curriculum based on the Pediatric ELNEC has been very successful as a we can adapt the content to our own population.

Starting the discussion with potential hires that we care for the pediatric population at the time of the interview and letting staff know up front that they might be asked to care for children is a must to prevent future issues. In addition, remember to include this language in their job description. Basic pediatric materials and the 'I feel' exercise during general orientation provided an excellent way to hardwire the goals and mission of the organization to care for those across the life span.

It is important to consider and be prepared that there will be those who cannot, for whatever reason, adapt to this new practice and may decide to leave your organization. While developing one program from the ground up, I had one nurse who left the agency because she could not see herself caring for pediatrics. In the big picture, one person, was not a huge impact, but it is something that needs to be addressed early on.

For the long term, continuing to provide annual educational sessions and precepting in the field is key. I also cannot stress enough the importance of ongoing debriefings and "I feel" sessions not only during orientation and the time of their visits, but at regular intervals provide a space for staff to express their concerns and successes. This allows the leaders to be observant, actively listen to staff concerns, provide time to debrief, and encourage the use of rituals to acknowledge difficult situations and pediatric deaths. The use of passing a stone to each other or as in our case, adding a butterfly to a beautifully painted board with a rainbow allowed staff time to grieve appropriately. In some cases, staff will also need time for additional self-care by taking time off from caring for the pediatric patient. It is imperative that we allow that in order for our staff to be able to do this work. Lastly, being actively engaged as lifelong learners in pediatric care and advocating at the legislative level, as well as having a pediatric family advisory board, will enrich the program and services provided.

For more information on pediatric hospice see [www.nhpco.org/wp-content/uploads/NHPCO\\_Pediatric\\_Facts\\_Figures\\_2023.pdf](http://www.nhpco.org/wp-content/uploads/NHPCO_Pediatric_Facts_Figures_2023.pdf)

## Some Resources:

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**Friedrichsdorf, S. J., Remke, S., Hauser, J., Foster, L., Postier, A., Kolste, A., & Wolfe, J.** (2019). Development of a pediatric palliative care curriculum and dissemination model: Education in palliative and end-of-life care (EPEC) pediatrics. *Journal of Pain and Symptom Management*, 58(4), 707-720.

**Friedrichsdorf, S. J., & Bruera, E.** (2018). Delivering pediatric palliative care: From denial, palliophobia, pallilalia to palliative. *Children*, 5(9), 120.

**Lafond, D., Perko, K., Fisher, D., Mahmood, L. A., & Hinds, P. S.** (2022). Impact of pediatric primary palliative care education and mentoring in practice. *Journal of Hospice & Palliative Nursing*, 24(1), 22-29.

**Li, J., Smothers, A., Fang, W., & Borland, M.** (2019). Undergraduate nursing students' perception of end-of-life care education placement in the nursing curriculum. *Journal of Hospice and Palliative Nursing*, 21(5), E12.

**Weaver, M. S., Chana, T., Fisher, D., Fost, H., Hawley, B., James, K., ... & Torkildson, C.** (2023). State of the Service: Pediatric Palliative and Hospice Community-Based Service Coverage in the United States. *Journal of Palliative Medicine*, published ahead of print. <https://doi.org/10.1089/jpm.2023.0204>



# The Pediatric End-Of-Life Information Online: An Overview of The PedEOL Care Research Group Website

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The University of Tennessee, Knoxville – College of Nursing hosts a comprehensive website focused on pediatric end-of-life care. Led by Dr. Lisa C. Lindley, PhD, RN, FPCN, FAAN (PI), the site was developed in 2019, and is continuously updated with research, policy, and education material for free use by individuals, families, PedEOL coalitions, policymakers, clinicians, researchers, and the general public. There is also information about the Pediatric End-of-Life Care Research Group and its mission and goals.

## Research Information

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Research information on pediatric-end-of life care, concurrent care, rural care, and methodologies and theories related to areas in end-of-life care and nursing researching is provided on the website. Information about the PedEOL Research Group's research projects is available, as well as lists and links to their research findings and articles with public access links.

## Advocacy Information

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Advocacy information is offered via tools and resources for state and federal concurrent care. These include state implementation documentation and federal implementation guidance documents issued to states on concurrent care via Medicaid, CHIP, and TriCare. Additionally, the website contains information on state and federal pediatric legislation on perinatal hospice, pediatric hospice, pediatric palliative care, and hospice that is currently under consideration, along with state Medicaid contacts. Printable materials for use in communicating with their policymakers and other stakeholders is available to download.

## Education/Training Information

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Audience specific education/training information on pediatric end-of-life care is provided for University of Tennessee students, hospice staff, and Medicaid administrators. Students can learn more about undergraduate and graduate nursing opportunities available to them through the Pediatric End-of-Life Care Group, and how research with the PedEOL group fits within their UTK College of Nursing studies and career. Hospice staff and Medicaid administrators can access a range of educational/training resources curated specifically for them. Infographics are also available, and these provide ready-made, free-to-print information on various aspects of pediatric end-of-life care from clinical considerations to state implementation, to simulations. Some limited examples of the Group's research as presented in poster form at conferences and workshops are also available.

In summary, the PedEOL Care Research Group website is intended to provide support and resources for those working, researching, or experiencing pediatric end-of-life care. The resources and tools provided on the site are evidence-based and verified so that the information is readily available in easy-to-use and read formats. It is updated regularly and continues to grow as the Group expands the scope of its PedEOL research and the information services the Group provides.

# Support of Hospices in Caring for Pediatric Patients in Washington State and the NWPPCC Region

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In the State of Washington, the hospice certificate of need program requires hospices to serve all hospice-eligible people in their service area, including all ages: from newborns to the elderly. In urban areas like the Seattle/Tacoma and Spokane areas, there are pediatric hospice and palliative care teams that follow pediatric patients at home. They have dedicated pediatric teams that include RN, MSW, Spiritual Care, and Pediatric Medical Director. As community providers or inpatient teams look for a hospice team who can serve a pediatric patient outside the urban hub, it can be a challenge. Rural hospices may only occasionally be asked to provide care for a child. As palliative care teams reach out with a referral, hospices are often reluctant to take on the responsibility to care for a child, as staff changes may mean that their previous "pediatric champion" is no longer there.

The Washington State Hospice and Palliative Care Organization (WSHPCO) Board prioritizes the care of children in our state. There is a monthly pediatric palliative care virtual networking meeting of stakeholders that has been meeting since the ACA first passed the provision for hospice concurrent care for pediatric patients. This group facilitated a major change in the state regulatory language which initially read: "treatments to achieve a disease-free state" to "life prolonging or curative treatments" while also receiving hospice care. The Pediatric Palliative Care networking group continues to meet monthly to problem solve access concerns and to address other pediatric palliative care issues. At the WSHPCO annual clinical conference each fall, presentations around pediatric palliative care and hospice continue to position this issue as a priority for education and discussion.

WSHPCO and the Oregon Hospice and Palliative Care Association (OHPCA), along with Seattle Children's Hospital and Oregon Health Sciences University's Doernbecher Children's Hospital, collaborated to found the Northwest Pediatric Palliative Care Coalition (NWPPCC) for the States of Alaska, Idaho, Montana, Oregon, and Washington. Through the NWPPCC, a monthly newsletter and twice annual meetings help provide education, advocacy, and peer support throughout the region for pediatric palliative care and hospice.

Over the past five years, Seattle Children's Hospital has prioritized the support of hospices in Washington State. Pre-pandemic this support included on-site visits to hospices to provide education. Since the pandemic began, virtual educational offerings have been provided which are tailored to a specific hospice's needs. Some rural

hospices have had three or four presentations, for new staff, and for ongoing education and support around hospice concurrent care. In addition, hospice medical directors have access to a pediatric palliative care trained pediatrician 24/7 to problem solve symptom management issues. Staff have access to the pediatric palliative care team including a nurse coordinator for questions and advice.

This outreach education has emphasized the similarities in caring for adults and children, as opposed to focusing on the differences between adult and pediatric care. Seattle Children's Hospital staff have found that pediatric and adult families have the same concerns around comfort and quality of life, and that hospice personnel are experts in these areas. And yet, we also know that the prospect of caring for pediatric patients can be intimidating to staff who seldom provide this care, so we try to demystify the work, with practical tips, resources, and by allowing ample time for questions.

One of the most important lessons we have learned is that relationships are important. Hospices need to know that the referring hospital or palliative care team will share as much information about the patient and family as possible, and that you will be available to help support them as they get to know the family and build rapport. When a referral is sent, we make sure to include contact for all of the key players at the children's hospital (providers, social worker, clinic nurse coordinators, etc.) so that hospices know who they can reach out to with disease specific concerns in addition to the palliative care team.

One example of a successful relationship with a hospice that primarily serves adults, is between Seattle Children's Hospital Palliative Care team and Hospice of the Northwest. This hospice serves a large geographic area with patients in Skagit and San Juan counties, as well as Whidbey Island in Island County. Many features make this service area unique for Hospice of the Northwest. They serve a rural area that is known for farming and recreation, with an area of over 2,000 square miles—some of which is only accessible by ferry. They creatively manage this area with staff that live both on and off the islands, many of whom have sheds in their back yards to store extra medical supplies and equipment. This group of hospice professionals have to navigate between islands via ferries that don't run 24 hours a day. None of the islands have pharmacies open seven days a week, which means that they must also be experts in anticipating what might be needed. This frontier-type situation in their service area, has helped to foster the initiative to navigate the frontier of serving pediatrics well.

Why is this hospice, with an average daily census like many other hospices, so well respected in their care of pediatric patients? As one of their referral sources, they have staff and physicians who are motivated and actively involved in getting to really know the kids they follow: what brings them joy, what quality of life looks like to them, and they accept the child and family's goals of care, without trying to fit them into the box of how adult hospice "works." This hospice has gone all in with pediatric care and by embracing it, they take a sense of pride in a job well done. That pride is apparent in all, from the people who answer the phone, their amazing staff, their medical directors, and executive director. They have cared for a child with heart failure from complex congenital heart disease, a teen receiving dialysis, a child who needed frequent blood transfusions because of liver disease, kids with cancer diagnoses, and kids with severe neurologic impairment. They have asked the Seattle Children's Hospital Palliative Care team to visit their hospice in person or via zoom several times to keep them current with training. They know they can call any time 24/7 with questions. They are great partners who communicate well with their referral sources, including when a child may need to be seen in an Emergency Department.

When two of their medical directors, Dr Anita Meyer and Dr Leslie Estep, were asked to share their thoughts about caring for pediatric patients, they provided wonderful insight. The following quotes capture how to serve pediatric patients successfully and respectfully within an adult-focused hospice.

"Adore the child. Interact with the child. It means everything to these families to be home. It is such an honor to be able to help with that."

"Don't become the hearse driving through the living room every visit."

Here are additional suggestions and advice from Dr Estep and Dr Meyer:

- Make/find a dose reference sheet for comfort meds for pediatric dosing. It makes clinicians feel more secure to see it in writing in readily found location.
- Help parents with their other children too. Offer more Social Work services and more spiritual care. Offer Art therapy, games, resources.
- Figure out activities that build memories.
- Our hospice team also brings so many skills in making memory mementos for the future...thumbprint pendants, etc.
- Provide more MD visits for these patients. Both to support the RNs who might be working at new skills and to improve your own skills/rapport/effectiveness.
- Try to find a local pediatrician or family doc who will support you for routine peds issues that may come up.
- Have a pediatric palliative care doctor for support.
- Keep a growth chart on kids with slowly advancing (neurodevelopmental disease) to help understand prognosis, demonstrate eligibility.
- Consider having two POLST forms, parents can decide which one it's time for.
- Have a relationship with a compounding pharmacy.
- Have a regular update for all RNs/MDs who may be covering for the patient to reduce their stress and improve quality/adherence to POC.
- If there's a change in condition or plan, communicate it to all staff who might be involved promptly.
- Prepare for the patient by reading about their rare disease AND know that the parent is likely more expert than you'll ever be. Be ready to say "I don't know." Be ready to be more collaborative. Be ready to flex around what may seem like unconventional or unproven medical beliefs.
- Expect slow movement from curative toward palliative.
- Ask about which specialty care clinics are helping families most...the children's nutritionist may be making care more burdensome with heavy emphasis on growth/calories. This can create so much guilt. Honoring how much parents know about what their child needs most is a good way to enter visits.
- These patients are both very rewarding to take care of and very difficult.
- Recognize the added stress of caring for a child with your staff in terms of both the clinical skills needed AND the emotional strain and provide support along the way. Consider having two nurses assigned to complex peds patients for extra back up. Consider having a peds patient count for 2 or 3 patients on the nurse's panel count.

We have worked closely with these physicians for many years, and so appreciate the great care they provide and their willingness to ask questions.

Additional recommendations we share with hospices in the NWPPCC region.

- <https://www.nhpco.org/pediatrics>
- Concurrent Care Medication Coverage
- <https://www.nhpco.org/wp-content/uploads/NHPCO-Medication-Flow-Chart- Apr-2020vFinal.pdf?msclkid=c95488eacfc911ec8819d2d7dbd12997>
- Pediatric End-of-Life Care Research | The University of Tennessee, Knoxville ([utk.edu](http://utk.edu))
- <https://courageousparentsnetwork.org/guided-pathways/pediatric-palliative-care-for-the-uninitiated/>
- Series of short videos created by an adult physician who had a child that received pediatric palliative care. Excellent for adult hospices caring for a child.
- [blueBook.pdf \(dfci.org\)](#) Pediatric pain and symptom management resource out of Dana Farber/Boston Children's Hospital.
- CPN | Courageous Parents Network. Great resource for parents and anyone working with children.
- Pediatric E-Journal | NHPCO Journal published four times a year with contributions from professionals and parents
- PPC Webinars Monthly webinars on various pediatric palliative care topics
- Pediatric track | Palliative Care Training Center ([uw.edu](http://uw.edu)) UW PPC certificate program
- <https://www.seattlechildrens.org/clinics/palliative-care-consultation/nwppcc/> NWPPCC website with many resources for the NWPPCC region.

# Reach Initiative: Regional Pediatric Education and Assistance Collaborative for Hospice Nurses

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## Introduction

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Currently, hospice is based in an adult-focused paradigm; however, caring for children and families at end of life is uniquely challenging, necessitating pediatric-specific training. Unfortunately, few hospice clinicians receive this vital education. A previous population-level survey of hospice nurses across Tennessee, Arkansas, and Mississippi demonstrated that the vast majority of nurses lacked training in pediatric palliative or hospice care, overwhelmingly felt uncomfortable caring for children, and emphasized the urgent need for pediatric-specific training.<sup>1</sup> In follow-up interviews, they also shared preferences for how this education should be delivered including engaging pediatric palliative care and hospice experts to provide content in an environment that builds community and solidarity.<sup>2</sup> The Regional Pediatric Education and Assistance Collaborative for Hospice Nurses (REACH) Initiative was launched in 2022 to address this critical education need in the hospice community.

## Building the REACH Initiative

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We partnered with key regional hospice stakeholders across the midsouth to form a Community Advisory Board (CAB) consisting of 17 members including hospice nurses, administrators, physicians, chaplains, and bereaved parents. The CAB worked alongside a multi-site Strategic Planning Council (SPC) of interdisciplinary pediatric palliative care clinicians and researchers. Each group met four times over the course of one year to conceptualize and develop a model to provide hospice nurses with access to pediatric-specific training and support.

## REACH Mission and Vision Statements

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**Vision:** All hospice nurses caring for children in our geographic region will have access to expert pediatric-specific training and support to empower them in delivering high quality, compassionate care to these children and their families.

**Mission:** We will achieve our vision by working collaboratively as an interdisciplinary Community Advisory Board and Strategic Planning Council whose efforts are aimed at developing an innovative model to provide education, resources, peer support, and community for hospice nurses in our region.

## REACH Model

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The REACH Initiative utilizes a “hub and spoke” tele-education model, in partnership with Project ECHO® (Extension for Community Healthcare Outcomes), to deliver resource-efficient training and support to community hospice providers by creating a network of shared knowledge and solidarity.<sup>3</sup> Through this model, free monthly tele-education sessions are provided to nurses who can also earn continuing education credits for attending.

Each session covers a core topic derived from our CAB recommendations, comprising an expert-led didactic followed by a case-based discussion to allow nurses to engage in real-time troubleshooting with pediatric experts. In response to our CAB highlighting the importance of hospice nurses building resiliency around caring for pediatric patients given the immense emotional toll, our sessions conclude with a brief mindfulness activity to help foster this resilience.

Additionally, we have developed a user-friendly website and listserv to provide further resources and community building. Our website houses information about the REACH Initiative and a registration portal, as well as a repository of session recordings and key resources that hospice nurses can use when in the home with a pediatric patient.

We have designed evaluation tools to assess the feasibility and acceptability of this model to hospice nurses, as well as to study the impact of this intervention on hospice nurse comfort with and knowledge around providing pediatric care.

## REACH Curriculum

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Our curriculum for the initial pilot phase of the REACH Initiative is comprised of 12 topics presented in the table below:

<b>Supporting Hospice Nurses Caring for Children: An Introduction to the REACH Initiative</b>	<b>Ethical Considerations in Pediatric Palliative and Hospice Care</b>
<b>Navigating Difficult Communication</b>	<b>Caring for the Technology-Dependent Child</b>
<b>Pain Management</b>	<b>Management of Respiratory Symptoms</b>
<b>Management of Emotional and Behavioral Symptoms</b>	<b>Management of Neurologic Symptoms</b>
<b>Management of Gastrointestinal Symptoms</b>	<b>Caring for the Actively Dying Child</b>
<b>Family-Centered Care</b>	<b>Grief and Bereavement</b>

## REACH Launch

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Prior to launching, we engaged in extensive collaboration with local, regional, and national organizations to promote the REACH Initiative in a grassroots manner. The REACH Initiative then held its first session with members across Tennessee in September 2022; currently, the Tennessee REACH chapter has 39 registered

participants representing more than 10 different hospice organizations. In partnership with the Louisiana Mississippi Hospice and Palliative Care Organization, the Gulf States Pediatric Palliative Care Consortium held their first REACH session in January 2023 and now has 77 registrants across three states representing over 25 different hospice organizations. Preliminary data demonstrate that our tele-education model is both feasible and acceptable to hospice nurses and that nurses have gained pediatric-specific hospice knowledge.

## Summary and Next Steps

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Through collaborative partnership with key hospice stakeholders in our region, we have developed an innovative educational intervention to address a critical need in the hospice community. Next steps will focus on wide-scale dissemination of this intervention to deliver resource-efficient, comprehensive support to hospice nurses throughout our region and beyond. For more information about joining the REACH Initiative in Tennessee or the Gulf States region, or to learn more about launching the REACH Initiative in your state, please feel welcome to contact Taylor Aglio or Ashley Autrey.

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# Pediatric Medication Management Considerations

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Pediatric symptom management can be challenging, not because children experience vastly different symptoms compared to adults or even require completely different medications, but because so many factors need to be considered when choosing therapy, such as the patient's age, weight, and possible side effects. But the symptoms seen are similar and the general principles of management are a good starting place. Patient specific factors will guide therapy. Consider consulting a pediatric pharmacist for assistance with medication selection and dosing in children.

## Medication Dosing

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Most medications are dosed based on weight (or body surface area) and recommended weight-based dosing varies based on developmental changes as children age. Reference guides list doses as either mg/kg/dose or mg/kg/day in divided doses. When patients have significant weight changes (which is typical as children grow), doses may need to be adjusted. During the first two weeks of life birth weight is typically used for dosing since neonates lose up to 10% of their birth weight and then regain it over the first 10-14 days.

## Medication Administration<sup>1-2</sup>

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Medication administration can be challenging in children for many reasons. These issues are further complicated in the palliative and hospice care setting. Children may not be able to swallow capsules/tablets, so liquid formulations are used more frequently. Unfortunately, not every medication has a commercially available liquid product. Compounded liquids may be necessary. Tablets may be crushed and dissolved in water in some situations, but palatability may be an issue, and the patient's dose may not be measurable using commercially available strengths.

Fortunately, numerous devices are available that may make administration a little easier, for example, a pacifier or nipple medicine dispenser for infants. For smaller volumes, an oral dosing syringe may be used to accurately measure the patient's dose and allow the medication to be squirted along the inside of the cheek (hopefully bypassing some of the taste buds). Ensure the oral dosing syringe used can accurately measure the medication volume. Larger syringes will not have smaller dosing increments. A 0.3 mL oral syringe is often needed for 0.05 mL increments. Doses should not be mixed in the infant's primary source of nutrition, especially an entire bottle. This could alter the taste of the feed and affect future feeds. If the infant doesn't finish their entire feed, they won't receive their entire dose. Toddlers may be influenced by distracting devices such as an alligator or elephant medication dispenser.<sup>3-4</sup> Remind families not to use common household measuring devices since these can be variable.

Taste masking sprays (e.g., Pill Glide®)<sup>5</sup> may help mask the taste of liquids or tablets. Sucking on an ice cube or ice pop before and after doses can minimize negative tastes. Many medications can be mixed with honey or chocolate syrup (or other flavors). Refrigerating certain liquids may improve palatability.

## Pharmacokinetics

Many pharmacokinetic parameters are altered in children (Table 1, Table 2), affecting how the body handles drugs. For example, drugs are typically absorbed more slowly in neonates, prolonging time to onset of action and peak levels. Hepatic metabolism (e.g., glucuronidation) is slower and matures around six months of age. Clearance is typically slower due to immature kidney function. At birth, serum creatinine levels are reflective of the mother's renal function. Glomerular filtration rate increases rapidly in the first two weeks of life (slower if premature). Once renal function begins to mature, serum creatinine levels are generally much lower than seen in adults since neonates have decreased muscle mass. Infant body composition can affect drug distribution. Due to the increased water composition and decreased fat composition, water soluble drugs (e.g., aminoglycosides) have increased volume of distribution, while lipophilic medications (e.g., LORazepam) have a lower volume of distribution. Serum albumin and protein concentrations are decreased in neonates. Therefore, drug binding to plasma proteins will be decreased, resulting in increased free drug (e.g., phenytoin). Some medications (e.g., ceftriaxone, sulfamethoxazole) displace bilirubin from protein binding sites. Neonates are unable to adequately excrete bilirubin, resulting in elevated bilirubin levels. Due to increased blood-brain barrier permeability, neonates are at risk for accumulation of bilirubin in the brain (kernicterus).

**Table 1. Developmental Alterations in Intestinal Drug Absorption<sup>6-9</sup>**

Functional Alteration	Neonate	Infants	Children
Gastric acid secretion	Reduced (pH >5)	Adult (pH 2-4)	Adult (pH 2-3)
Gastric emptying time	Variable	Prolonged	Prolonged slightly
Intestinal motility	Slower	Increased	Normal
Intestinal surface area	Reduced	Near adult	Adult pattern
Biliary function	Immature	Near adult	Adult pattern
Microbial colonization	Acquiring	Near adult	Adult pattern

**Table 2. Neonatal Pharmacokinetic Alterations<sup>7-9</sup>**

Function	Alteration	Neonatal Function	Compared to Older Children
<b>Enteral Absorption</b>	Gastric pH	High at birth (6-8) Decreases after 24 hours	Decreased bioavailability & increased absorption of acid-labile drugs
	Gastric emptying	Feeding dependent; Variable	Unpredictable rate of drug delivery to intestinal mucosa
	Intestinal motility	Slower	Prolonged time to achieve maximum plasma concentration
	Lipase levels & bile salts	Decreased	Decreased bioavailability of lipid soluble drugs
	Efflux transporters	Reduced	Altered bioavailability
<b>Rectal Absorption</b>	Permeability and first pass to portal circulation	Higher if administered into distal rectum; If deep administration, first-pass effect may alter bioavailability	Increased bioavailability if drug absorbed into lower or distal segment of rectum Typically, increased absorption

Function	Alteration	Neonatal Function	Compared to Older Children
<b>Intramuscular Absorption</b>	Perfusion, muscle mass, and activity	Usually decreased Increased capillary density in neonatal muscle	Decreased rate of absorption due to decreased cardiac output Potential local trauma
<b>Transdermal Absorption</b>	Surface area-to weight ratio	Increased	Increased absorption
	Stratum corneum	Incompletely formed	Increased absorption
	Vasomotor control	Immature	Increased absorption
<b>Inhalation</b>	Mucosal permeability	Increased	Systemic exposure
<b>Distribution</b>	Total body water	Increased volume of distribution	Reduced peak and threshold concentrations at weight dosing
	Extracellular water	Increased	Further expands volume of distribution
	Body fat composition	1% of adult level in preterm and 15% in term infants	Lower lipophilic drug disposition
<b>Blood-brain Barrier</b>	Permeable barrier	Immature	Increased potential permeability
<b>Protein Binding</b>	Plasma proteins	Decreased	Increased free/unbound drug available to receptors
<b>Metabolism</b>	Biotransformation primarily involving hepatic enzymes	Decreased	Drug dependent: renders some drugs more active and some less active; often affects clearance
<b>Hepatic Blood Flow</b>	Extraction or removal of active drug by metabolism	Increased cardiac output to liver increases hepatic flow	Increased clearance of drugs with high intrinsic hepatic clearance
<b>Renal Elimination</b>	Glomerular filtration	Dependent on renal blood flow; reduced in premature infants; reaches adult levels by two years	Most drugs have delayed clearance with increased half-life elimination with individual variability
	Tubular secretion	Reduced active secretion	Delayed excretion and prolonged half-life
	Tubular reabsorption	Reduced	Dependent on renal blood flow, glomerular filtration rate, urine output, urine pH, and tubular secretion
<b>Clearance</b>	Multisystem function	Reduced	Accumulation

## Age Restrictions

These pharmacokinetic differences result in age restrictions with medication use in children (Table 3; Table 4).

**Table 3. Example Medications with Age Restrictions<sup>1,10-15</sup>**

Medication*	Age Guide <sup>†</sup>	Concerns
ceftriaxone (Rocephin <sup>®</sup> )	Avoid <2 months	Hyperbilirubinemia
chloramphenicol	Avoid in children	Gray Baby Syndrome
<b>Cough &amp; cold products<sup>11-12</sup></b> <ul style="list-style-type: none"> <li>■ Antihistamines</li> <li>■ Decongestants</li> <li>■ Cough suppressants</li> </ul>	<ul style="list-style-type: none"> <li>■ FDA &gt;2 years</li> <li>■ CHPA &gt;4 years</li> <li>■ AAP &gt;6 years</li> </ul>	<ul style="list-style-type: none"> <li>■ No safety or efficacy data in children</li> <li>■ Reports of seizures, coma, death</li> </ul>
<b>Fluoroquinolones</b>	<ul style="list-style-type: none"> <li>■ ciprofloxacin &gt;1 year</li> <li>■ levofloxacin &gt;6 months</li> </ul>	<ul style="list-style-type: none"> <li>■ Osteonecrosis</li> <li>■ Tendon rupture</li> </ul>
haloperidol (Haldol <sup>®</sup> ) <sup>13</sup>	>3 years	Increased dystonic reactions
phenytoin (Dilantin <sup>®</sup> )	All ages	Decreased protein binding
promethazine (Phenergan <sup>®</sup> ) <sup>14-15</sup>	>2 years	Respiratory depression
sulfamethoxazole/ trimethoprim (Sulfatrim <sup>®</sup> )	>2 months	<ul style="list-style-type: none"> <li>■ Hyperbilirubinemia</li> <li>■ Bone marrow suppression</li> </ul>
<b>Tetracyclines</b>	>8 years	Tooth discoloration
valproate (Depakene <sup>®</sup> )	>2 years	Hepatotoxicity

\*List is not all inclusive. † FDA-approved age may vary by indication and product. FDA- Federal Drug Administration. CHPA- Consumer Healthcare Products Association. AAP- American Academy of Pediatrics.

## Pain Medication Considerations<sup>1,10</sup>

Unfortunately, several pain medications have restrictions for use in children. Neonates eliminate opioids more slowly than adults, but elimination reaches and exceeds adult levels within the first year of life. For example, children less than 11 years of age have significantly higher morphine clearance and volume of distribution compared to adults.<sup>22</sup>

**Table 4. Pain Medications with Age Restrictions<sup>1,10,16-24</sup>**

Medication*	Age Guide <sup>†</sup>	Concerns
aspirin	>12 years	Reye's syndrome
Codeine <sup>16-21</sup>	Adults	<ul style="list-style-type: none"> <li>■ Black Box Warning</li> <li>■ Respiratory depression</li> <li>■ Variable pharmacokinetics</li> </ul>
Ibuprofen (Motrin <sup>®</sup> )	>6 months	<ul style="list-style-type: none"> <li>■ Glucuronidation</li> <li>■ CYP2D6 (and others) metabolism</li> </ul>

Medication*	Age Guide†	Concerns
<b>fentaNYL</b>	<ul style="list-style-type: none"> <li>■ Transdermal: &gt;2 years</li> <li>■ Transmucosal: Adults</li> <li>■ IV: &gt;2 years (used off-label infants)</li> </ul>	<ul style="list-style-type: none"> <li>■ Transdermal patch- erratic absorption, difficulty titrating dose</li> <li>■ Transmucosal- choking hazard</li> </ul>
<b>HYDROcodone/ acetaminophen (Lortab®)</b>	<ul style="list-style-type: none"> <li>■ &gt;2 years (with acetaminophen)</li> <li>■ Oral solutions</li> </ul>	CYP2D6 metabolism
<b>HYDROmorphine (Dilaudid®)</b>	>6 months	Glucuronidation function
<b>morphine (Roxanol®)<sup>22</sup></b>	>6 months	Glucuronidation function
<b>oxyCODONE (Roxicodone®)</b>	>18 years	CYP2D6 metabolism
<b>traMADadol (Qdolo®)<sup>23-24</sup></b>	>16 years	<ul style="list-style-type: none"> <li>■ CYP2D6 metabolism</li> <li>■ Decreases seizure threshold</li> </ul>

\*List is not all inclusive.

Aspirin is typically avoided for pain management in children (<12 years of age) due to the risk of Reye’s syndrome (acute encephalopathy with liver damage). Ibuprofen (Motrin®) should not be used in infants less than six months of age since infants are unable to adequately metabolize it (hydroxylation via CYP2C9 and CYP2C8 enzymes in the liver).

Codeine and codeine-containing products should be avoided in pediatric patients due to the highly variable pharmacokinetics and side effects, as well as lack of evidence and safety.<sup>16-18</sup> Codeine is routinely converted to morphine by the CYP2D6 enzyme in the liver. People can have varying degrees of CYP2D6 activity. Poor metabolizers are deficient in CYP2D6 and have inadequate therapeutic response from codeine. On the other hand, people with higher-than-normal CYP2D6 activity, considered ultra-rapid metabolizers, may have supra-therapeutic response and increased risk of adverse reactions.<sup>19</sup> The FDA does not recommend the use of codeine in children, specifically following tonsillectomy and/or adenoidectomy, due to reports of respiratory depression and death.<sup>FDAx2</sup>

Similarly, hydrocodone must be metabolized by CYP2D6 to hydromorphone to provide most of its analgesic effect. Hydrocodone is also metabolized via CYP3A4 and other non-CYP pathways as well. Hydrocodone containing products are not recommended in children <2 years of age and there is very limited dosing information in this population. Tablets and capsules are only approved for use in adults. Additionally, immediate-release hydrocodone is only available in combination with acetaminophen which may make rapid titration difficult and adds the hepatotoxicity risk. Extended-release hydrocodone products are not approved for use in children.

Fentanyl is often considered in patients that are non-compliant with frequent medication administration or need a longer acting agent. It can be a good choice for opioid rotation in situations of neurotoxicity or dose-limiting side effects since it is structurally different than other opioids. Fentanyl is not recommended in children less than two years of age, but the IV formulation is often used off-label in this population. The transdermal patch should be used with caution in young children and should not be started on opioid-naïve patients. The smallest dosage form available is 12.5 mcg/hr. At a minimum, the patient would have to be receiving 25 mg/day of oral morphine equivalents to consider transitioning to fentanyl transdermal patch. Transdermal fentanyl typically isn’t started in patients receiving less than 60 mg/day oral morphine equivalents. Infants generally have increased absorption of medication topically since their skin is thin and not a very effective barrier. Infants may also have decreased fat disposition making it difficult for a depot layer to form. Fentanyl is extremely lipid soluble and therefore penetrates the CNS quickly. The transmucosal fentanyl products are not recommended in children less than 18 years of age, this includes the buccal film, buccal tablet, and oral lozenge, which would all be choking hazards for a young child.

Morphine is considered the gold standard for pain management and is typically first line in most patients. Although it does not have age restrictions associated with it, infants less than six months of age require much lower doses

(0.08 mg/kg/dose) due to their decreased ability to metabolize morphine and decreased clearance. Infants are at increased risk of toxicity, such as respiratory depression, but morphine can be completely safe in this population as long as it is dosed appropriately.

Oxycodone is also metabolized by CYP2D6 and CYP3A4. Dosing information is not available for oxycodone in infants <6 months of age. Immediate release products are approved for use in adults; while extended-release products are approved for use in children >11 years. Oxycodone is often used in patients with renal dysfunction.

Although tramadol is metabolized via CYP2D6 to the more potent O-desmethyltramadol, tramadol itself is a weak mu-receptor agonist with additional effect inhibiting norepinephrine/serotonin reuptake. Tramadol is not approved for use in children though and dosing is not available for children less than four years of age.<sup>21,24</sup> One case report described a five-year-old girl who experienced respiratory depression after receiving a single dose of tramadol following a tonsillectomy/adenoidectomy.<sup>23</sup>

## Nausea and Vomiting Considerations<sup>1,10</sup>

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Approach nausea and vomiting management similar to adult management. Evaluate potential causes and identify mechanisms involved. Then focus on medications that target associated neurotransmitters. Since haloperidol (Haldol®) is a potent dopamine antagonist, it is often first line for chemoreceptor trigger zone (CTZ) nausea/vomiting in adults. Haloperidol (Haldol®) is not approved for use in children <3 years of age though and may have increased incidence of dystonic reactions in children.<sup>13</sup> Other options, such as metoclopramide (Reglan®), may be appropriate to trial before haloperidol in infants and toddlers.

Children tend to exhibit more extrapyramidal side effects from phenothiazines (e.g., chlorpromazine, prochlorperazine, promethazine), especially when given during acute viral illnesses.<sup>14-15</sup> Promethazine specifically has a black boxed warning for increased risk of respiratory depression in children less than two years of age.<sup>15</sup> Diphenhydramine (Benadryl®) can be used to treat EPS from phenothiazines. However, antihistamines are not approved for use in less than two years of age (due to reports of serious adverse effects including respiratory depression and seizures) and should be used cautiously in children less than six years of age.<sup>11-12</sup>

## Constipation Considerations<sup>1,10</sup>

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Osmotic laxatives are often considered first line for management of constipation in young children. Polyethylene glycol 3350 (PEG 3350, MiraLAX®) is commonly used off-label to treat constipation in children and is generally considered safe. The effects of long-term use (>11 months) or large doses (>1.5 g/kg/day) of PEG 3350 in children are unknown. The FDA has received reports of metabolic acidosis and neuropsychiatric events in children taking PEG 3350; however, direct causality with the drug has not been established. In 2014, the FDA decided no action was necessary based upon available data and recommends close monitoring for signs of metabolic acidosis or neuropsychiatric changes.<sup>25</sup> PEG 3350 remains one of the most common medications for management of constipation in children. PEG 3350 is easy to administer, has minimal reported adverse drug events, and proven efficacy.<sup>26-32</sup> The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) recommends the use of PEG 3350 as first-line maintenance treatment for constipation in children.<sup>26</sup>

Stimulant laxatives are considered second line in children, but may be appropriate in some patients, especially those receiving opioids. Senna (Senokot®) is approved for patients >2 years and tends to have less cramping compared to bisacodyl (Dulcolax®) (approved >6 years of age). A combination liquid product containing senna and docusate (Senokot-S®) is not commercially available. Palatability may be a concern for both senna and docusate liquid.

## Secretions Considerations<sup>1,10, 33, 34</sup>

Atropine ophthalmic solution is often used sublingually (SL) to manage secretions at end of life. One drop of atropine 1% ophthalmic solution contains approximately 0.5 mg atropine. Consider systemic exposure patient will receive when using in children. If using for chronic secretion management, avoid doses that would result in systemic exposure greater than that given for other indications (0.01 – 0.05 mg/kg) to minimize potential cardiovascular effects. Consider diluting to 0.25% or 0.5% with water to decrease systemic exposure (Table 4). Titrate dose based on response. Cardiovascular effects are less of a concern as patient approaches end of life.

**Table 5. Atropine Dosing for Secretions in Children<sup>1</sup>**

Weight	Concentration	Dose	Route	Frequency	Recipe
<10 kg	0.25%	1 drop	SL	Q6H PRN	Combine 2.5 mL atropine 1% with 7.5 mL water
11-24 kg	0.5%	1 drop	SL	Q6H PRN	Dilute atropine 1% with equal part water
>25 kg	1%	1 drop	SL	Q6H PRN	Commercially available ophthalmic solution

Glycopyrrolate has a long duration of action and does not cross the blood brain barrier, thereby reducing the risk of central nervous system (CNS) side effects. These characteristics make glycopyrrolate a good option for chronic use.

## Comfort Care Kits

Comfort care kit use is more challenging in children. A one-size-fits all kit isn't appropriate due to age restrictions of common comfort medications. For example, haloperidol is not approved for use in children less than three years of age and has an increased incidence of dystonic reactions in children. Therefore, haloperidol would not be the most appropriate agent to include in a comfort care kit for a child less than three years of age. Including medications that are not appropriate in all age groups would increase waste. Medications are dosed based on weight in children; therefore, patient specific doses are necessary. Specific patient doses help determine the most appropriate medication concentration to order when liquid formulations are required. Smaller doses may need a less concentrated formulation to ensure measurability. Conversely, some patients may need higher concentrations to ensure minimal medication volume. This makes choosing a specific concentration or even volume or quantity to include in symptom management kits difficult.

The Centers for Medicare & Medicaid Services (CMS) requires individual medications be reported separately. Therefore, medications cannot be billed as a "kit" and should be filled and reported individually. These regulations decrease the utility of comfort care kits. While comfort care kits provide a ready source of symptom management medications for end-of-life care, they can also be a source of waste and duplication of therapy. Multiple different comfort care kits may be necessary to allow for more age-specific symptom management. In many situations though, the patient already has orders for one or more of the kit medications. Proactively preparing for the specific symptoms each individual child may experience (including common symptoms seen with his/her life-limiting condition and addressing child and caregivers' concerns), may provide more effective symptom management for children.

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# Pediatric Grief and Bereavement Resources

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## Helpful Resources:

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- Compassionate Friends-The Compassionate Friends, [www.compassionatefriends.org/](http://www.compassionatefriends.org/)
- Courageous Parents Network, <https://courageousparentsnetwork.org/>
- Perinatal Palliative Care Resolve Through Sharing Position Paper, <https://courageousparentsnetwork.org/>
- Grief and Bereavement Education and Support, [www.choc.org/programs-services/child-life/grief-bereavement-education-support/](http://www.choc.org/programs-services/child-life/grief-bereavement-education-support/)

## Guides and Books:

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- "When grief is new: A Guide for Parents and Families" [www.bostonchildrens.org/bereavement](http://www.bostonchildrens.org/bereavement), published by Constable Robinson, 2010.
- Contents of this guide have been written by Sue Morris and adapted from: Overcoming Grief: A Self-Help Guide Using Cognitive Behavioral Techniques by Sue Morris, published by Basic Books, 2008.
- "An Introduction to Coping with Grief, by Sue Morris, published by Constable Robinson, 2010.
- [www.scholastic.com/parents/books-and-reading/raise-a-reader-blog/7-touching-books-to-help-kids-understand-death-and-grief.print.html](http://www.scholastic.com/parents/books-and-reading/raise-a-reader-blog/7-touching-books-to-help-kids-understand-death-and-grief.print.html)
- "7 Touching Books to Help Kids Understand Death and Grieving" by Christie Burnett "
- Recommended Books for Children Coping With Loss or Trauma by the National Association of School Psychologist, [www.BooksforChildrenDealingWithLossorTrauma/](http://www.BooksforChildrenDealingWithLossorTrauma/)

## Hospice Bereavement Programs:

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- Hospice Foundation of America, [www.hospicefoundation.org/](http://www.hospicefoundation.org/)
- The National Hospice & Palliative Care Organizations (USA), [www.nhpco.org/](http://www.nhpco.org/)
- Hospice Federation of Massachusetts, [www.hospicefed.org/](http://www.hospicefed.org/)

## National Camps:

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The following are a list of bereavement camps for children, parents and families.

- **Camp Erin-the Moyer Foundation**,  
[www.moyerfoundation.org/](http://www.moyerfoundation.org/)
- **Camp Swan**, 3 days/2 nights camp for children ages 7-12 who have lost someone significant in their lives. Camp Swan Mississippi is held each spring at Camp Wilkes in Biloxi, Mississippi. Camp Swan-New Orleans will be held each fall at Camp Living Waters in Loranger, Louisiana.  
[www.akulafoundation.com/camp-swan/](http://www.akulafoundation.com/camp-swan/)

## On-line sites:

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

**"The National Center for Grieving Children & Families"**

[www.grief.com](http://www.grief.com)

**"Help for Grief Because LOVE Never Dies."**

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

**"a peer support organization focused on the caregiver experience."**

[www.grief.com](http://www.grief.com)

**"because Love Never Dies" One day seminars, online grief workshops, videos.**

[www.abedformyheart.com](http://www.abedformyheart.com),

**This is a bereaved mom's blog and website.**

[www.stjude.org/bereavement](http://www.stjude.org/bereavement)

[www.modernloss.com](http://www.modernloss.com)

[www.journeysofhopehealingandhealth.com/](http://www.journeysofhopehealingandhealth.com/)

[www.hopefamilycareministries/](http://www.hopefamilycareministries/)

# 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.

## 1. UPCOMING Conferences:

- **Optum Hospice Annual Conference**, September 22, Virtual! Registration is now open and there are pediatric sessions during this FREE conference. [Register now](#).
- **The NHPCO 2023 Annual Leadership Conference (ALC2023)** is the premier conference for leaders and aspiring leaders working to advance the field of hospice and palliative care. ALC2023 is a hybrid conference with in-person events held at the Statehouse Convention Center in Little Rock, Arkansas, and a virtual conference portal available for three months.
  - **Preconference** | September 30 – October 1
  - **Main Conference** | October 2 – 4
  - **On-Demand Access** | October 2 – December 31

September 14 is the last day to lock in the [Advance Rate](#). View conference details below and join [ALC2023](#) to be a part of pioneering conversations that spark bold, innovative thinking.

- [Conference Schedule at Glance](#)
- [In-Person Educational Sessions](#)
- [On-Demand Session Library](#)

- **AAHPM & HPNA Annual Assembly 2024** will be in Phoenix, Arizona in March. [Register](#) for more information.
- **The 2024 NHPCO Interdisciplinary Team Conference** will be held in April Virtually. Call for proposals will open in September. More information can be found on [the NHPCO website](#).

## 2. 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 get in touch with Christy at [Christy.Torkildson@gcu.edu](mailto:Christy.Torkildson@gcu.edu) or Suzanne Toce at [tocess@gmail.com](mailto:tocess@gmail.com).

**Issue Topics: 2023** (Note: Subject to Change at Work Group's Discretion)

- **Issue #73: Pain and Symptom Management.** In reviewing the main pain/symptoms of pain, nausea/vomiting, constipation, anxiety/agitation/delirium, respiratory distress/secretions, dyspnea, autonomic dysfunction, and seizures we hope to present an interdisciplinary approach to management of these symptoms. In your practice, how can you contribute to the care of an infant, child, adolescent or young adult dealing with pain or any of these symptoms? Interested? Please contact Christy at [Christy.Torkildson@gcu.edu](mailto:Christy.Torkildson@gcu.edu). Or Suzanne at [tocess@gmail.com](mailto:tocess@gmail.com) or Chuck at [charles\\_corr@comcast.net](mailto:charles_corr@comcast.net)

3. **2024:** Let us know your ideas! What topics would you like to see addressed in the Pediatric e-Journal?
4. **Our 75th Issue will be distributed in May of 2024!** What do you think we should include in this special issue?
5. **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.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics). Also, more palliative care resources are available at [www.nhpc.org/palliativecare](http://www.nhpc.org/palliativecare), including:

- Community-Based Palliative Care
- Legal and Regulatory Resources
- Webinars and Courses
- Brochures in English and Spanish for families
- Plus, more for NHPCO members

6. **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!

## Previous Items of Interest:

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7. **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](#).
8. **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)
9. **[End-of-Life Nursing Education Consortium \(ELNEC\) project](#)** has several upcoming courses; click on the name for more information.
10. **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!
11. **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](#).
12. **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](#).

13. **[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](#)

14. **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!](#)
15. **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](#)
16. **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!
17. **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.
18. **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.

19. **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*.

## 20. 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.

## 21. 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

### **Palliative Care Resources for Care Aids and Family**

- *Integrating a Palliative Approach: Essentials for Personal Support Workers, 2nd Edition; 1926923162*
- *Integrating a Palliative Approach: Essentials for Personal Support Workers 2nd Edition – Workbook; 9781926923178*

This textbook is a rare text that engages you with its warmth and heart—an essential resource for all frontline caregivers and family members supporting loved ones. The companion workbook engages learners through reflective activities, crossword puzzles, worksheets and interactive projects. Video and podcast libraries available on the Life and Death Matters website. <https://lifeanddeathmatters.ca/>

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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