Pediatric e-Journal

HOME CARE AND COMMUNITY CARE

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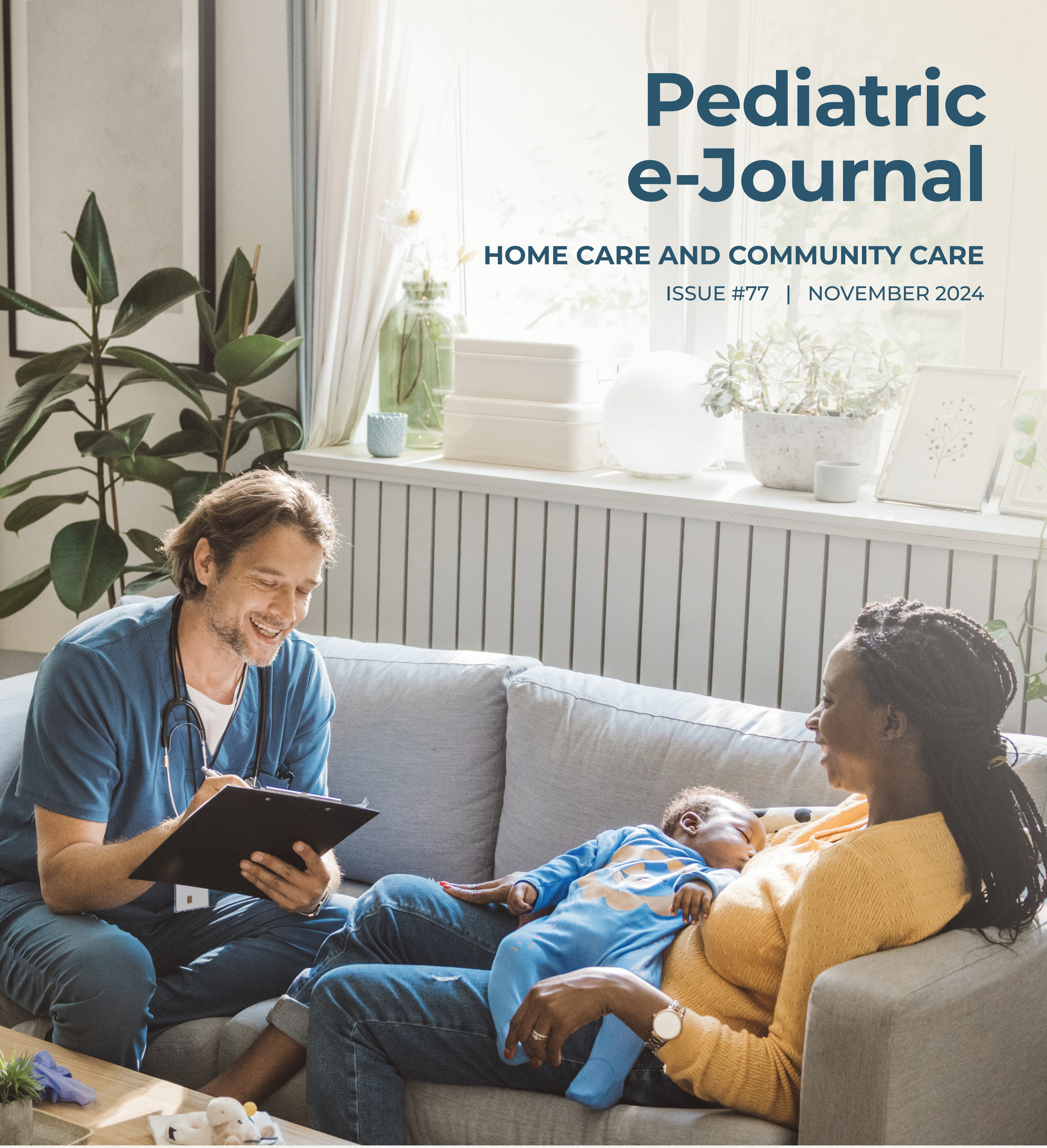

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Pediatric e-Journal Pediatric Palliative and Hospice Care

Issue #77 | November 2024

Issue Topic: Home Care and Community Care

Welcome to the 77th issue of our Pediatric e-Journal. Our focus in this issue is on subjects involving pediatric hospice and palliative home care and community care. Because home and community care represent a large portion of services delivered in pediatric hospice and palliative care, perhaps it should not be surprising that many contributors have offered articles for this issue. Of course, we recognize that no single issue would be capable of providing exhaustive coverage of these subjects, but we hope that the articles offered here will spark broad discussion of this subject area.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Hospice and Palliative Care Organization, now the National Alliance for Care at Home (the Alliance). The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Melissa Hunt. Chuck Corr is our Senior Editor. Archived issues of this publication are available at www.nhpco.org/palliativecare/pediatrics.

Comments about the activities thePediatric Advisory Council, its e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are open to suggestions for the four issues that will follow in 2025. Our tentative plans are for Issue #78 to address Interdisciplinary Team Dynamics and for Issue #79 to address Community Bridge of Support. If you have any thoughts about these topics or other subjects for future issues in 2025 and/or potential contributors (including yourself?), please contact Christy Torkildson at Christy.Torkildson@gcu.edu or Melissa Hunt at melissahunt3-1@hotmail.com.

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

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Table of Contents

Issue #77 | Home Care and Community Care

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

This article by its Chief Executive Officer introduces the National Alliance for Care at Home, a new organization resulting from the merger of the National Association for Home Care & Hospice and the National Hospice and Palliative Care Organization. Dr. Landers briefly describes his background in this field and highlights the role of pediatric care in the new organization.

In this article, the author describes the birth and short life of her firstborn daughter. Riley Marie was born with a life-limiting diagnosis of Trisomy 13. Because this condition is a spectrum and each child is unique, Riley’s parents “decided to follow Riley’s lead and to make care decisions based on what we felt was best for her.” They worked with a perinatal hospice program, gave Riley time in the NICU to stabilize while working with a palliative care doctor to refine their goals for her care, brought her home with support from a hospice nurse, and did many things to enrich her life. Her mother writes that “Riley not only had a beautiful life, but a beautiful death, too.” She adds, “I have so much more I could say about our journey, as it will never truly end. For this article, I will say that I’m grateful for the decisions we made for Riley’s life. There are times when I miss her deeply, and I feel guilty for not doing more or wishing for a different outcome. But in the end, I know that if I were to do it again, we’d make the same decisions. They were right for her. Our time together was short, but it was beautiful and incredibly meaningful.”

This is a collaborative parent perspective article representing the views of 11 parents of children with medical complexities and compiled by national parent advocate Dannell Shu. Over half of these parents are actively caring for their HopeKid, 27% are bereaved, 18% are both. You will want to read the article to learn from their wisdom that represents a combined experience of 95 years.

A Family's Financial Fairytale: What It Teaches Us about Paying Parent Caregivers and What Is Possible p. 12

Dannell Shu, Levi's Mother & Parent Advocate

In this article, an experienced, articulate, and wise mother describes the "financial fairytale" she and her family lived through in caring for a child with medical complexity who lived just beyond his seventh birthday. She calls this a "fairytale" because it is so far beyond the imagination of most parents and because "The patchwork of financial resources (health insurance, Medicaid, waivers, grants, programs) available to each child varies greatly by state, and many times by county." She adds, "So much of it depends on the foundation that was laid, the people you encounter, and barriers they help you navigate." Reading about the struggles faced by this family and the financial resources that helped them supports Dannell's call for additional clinician and parent advocacy to improve things in the future.

The Need for a Paid Parent Caregiver Program p. 16

Yasmina Halim, Lily's mother

In this article, the mother of a child who was diagnosed with Juvenile Tay-Sachs disease at age 7½ makes an articulate case for a paid parent caregiver program. Yasmina describes how their lives were changed when they were told that Lily had a rare and eventually terminal condition. While Lily is now 11 years old, the 3½ years since her diagnosis have posed emotional, financial, and physical challenges for her single mother with another child in the family. She writes, "The Medicaid waiver program in Florida, which is meant to provide assistance for families with children who have serious medical needs, has a waitlist that exceeds 10 years, with no fast-tracking even for those with terminal diagnoses. It took me 2.5 years of relentless advocating before finally receiving some assistance, and even then, it is not enough." Through this article and as part of a parent advocacy group in her state she has advocated for a paid parent caregiver program as both essential and life-changing.

Private Duty Nursing and Pediatric Hospice Care p. 18

Tanna B. Jensen-Nelson, BSN, RN

This article describes a program of private duty nursing (PDN) services for children with medical complexity. The author's sensitivity to the needs of such children and families began while growing up in a rural area where her mother "often provided private services to people in our area where no company would go." The author writes: "These experiences showed me just how important it was to keep kids home with their families, where they belong." As an adult, after qualifying as a nurse, she describes her involvement in a program providing PDN services, argues for the collaboration of PDN with pediatric hospice programs, and offers an illustrative case example.

Adjusting to Care in a Home-Based Pediatric Hospice and Palliative Care Program after Working in a Hospital Setting p. 23

Krista Jackson, RN, Erica Armstead, MSN, RN, & Jennifer Palmer, MSN, RN, MA, CHPPN

This article offers three related perspectives. First, a nurse manager in a home-based pediatric hospice and palliative care program explains why she asks nurses seeking to join her program where they have worked previously and how she can support them as they transition to her program. Second, a nurse who had worked in adult hospice care describes the issues she faced and how she dealt with them in moving to pediatric hospice care. Third, a nurse who had worked in postpartum care describes the reactions of her colleagues when she moved to pediatric home care and what she did to prepare herself for this transition. The article ends with a brief conclusion about what can be learned from these three nurses.

Boundaries in Home Healthcare p. 26

Sarah Schroyer, DNP, RN, CHPN, NE-BC, CNE

According to this author, “Professional boundaries in nursing [and in other healthcare professions] refer to the limits that define the therapeutic relationship between nurses and patients…These boundaries ensure that the relationship remains focused on the patient’s needs and is grounded in professionalism, respect, and ethical behavior. Nurses must maintain professional boundaries to safeguard both their own well-being and that of their patients. These boundaries play a crucial role in ensuring patient-centered care, protecting nurses from burnout and compassion fatigue, and preventing ethical dilemmas that can arise from blurred roles or inappropriate relationships with patients. This responsibility takes on new dimensions when care occurs in a home setting.” The article then describes different types of boundaries, how nursing boundaries shift in home care (the unique nature of home healthcare, boundary challenges in home care, and pressure to accommodate more flexible boundaries), consequences of failing to maintain boundaries in home care, and strategies for maintaining boundaries in home care.

Protecting Our Youngest Patients and Their Caregivers: Navigating Safety in Pediatric Home Care p. 31

Kristen Wheeler

This article begins by noting that “Pediatric caregivers balance clinical duties with behavioral management, family dynamics, and unique environmental hazards—often in homes that lack the structured safety of a hospital setting.” It then goes on to “highlight some of these challenges and consider strategies tailored to the pediatric home care environment.” The primary topics that are considered include: Recognizing Pediatric-Specific Risks in Home Care; Addressing Environmental Hazards: Firearms, Medications, and Other Risks; Implementing Safety Protocols for Pediatric Home Visits; Creating a Safety Partnership with Families; and Supporting Caregiver Safety Through Policy and Resources.

Barriers to a Safe and Effective Discharge Home for a Neonate on Hospice Care p. 34

Jennifer Palmer, MSN, RN, MA, CHPPN, Jennifer Nichols, RN, PNP, and Marilyn A. Fisher, M.D., M.S.

This article offers a detailed analysis of a case in which a mother "obtained regular obstetric care from her doctor in a country outside the United States. Three months before her baby was due, her doctors noted that the fetus had a complex cardiac anomaly. Not having the resources in her country to tackle such a complex problem, she was counselled to transfer her care, and the future care of her neonate, to a medical center in the United States that had expertise in pediatric cardiology." After transfer to the U.S., "Careful evaluation of the fetus here by Maternal Fetal Medicine, Pediatric Cardiology, and Pediatric Cardiothoracic Surgery revealed that the fetus likely had a complex cardiac malformation (hypoplastic right ventricle) which might not be surgically correctable, but might be able to be surgically palliated." The article then details a history of first admission to an NICU, discharge home, problems at home, second admission to the NICU, hospice collaboration, and eventual discharge home. The authors detail barriers to care throughout this history.

Determining Medication Coverage for Children Receiving Concurrent Care Hospice in the Home p. 39

Melissa Hunt, PharmD, BCPPS

This article employs an extended patient example to illustrate how medication coverage can be determined for children who are receiving hospice concurrent care in the home. As the article indicates, "Prior to concurrent care, children and families commonly discontinued hospice care to seek more aggressive care in the acute care setting, used the emergency department service for acute symptom episodes, or delayed entry into hospice care as they hoped for a cure. Hospice care and subspecialty care were primarily separate." Because these breaks in service no longer apply under concurrent care, it is important to show how hospice care and subspecialty care can and should work together. As the article indicates, "Concurrent Care plans of care are often complex and must factor in uncertain disease trajectories, complex chronic conditions requiring many subspecialists, difficulty delineating differences between comfort and life-prolonging entities of the care plan, and complications from medications and treatments." In addition, two different payment models must be coordinated. Challenges arise because, even though concurrent care is a federal mandate, implementation is state specific. The article ends by offering tips for successful implementation of concurrent care.

Massage therapy offers “symptom management and psychosocial support by way of skilled touch and therapeutic presence to children and young adults managing serious illness.” The author argues that massage therapy for pediatric palliative populations is quite different from massage therapy for healthy adults as offered by community providers. She details the differences in this article and describes logistical challenges in delivering PPC home care. The article concludes that this form of massage therapy is “about enhancing the quality of life for kids who are more than their illnesses, who have their own unique stories to tell, no matter the extent of their medical challenges and how much time they have left to live.”

The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit is a feature of the Medicaid program to which enrollees aged 21 and younger are entitled. According to this author, EPSDT is widely misunderstood, but “At the core of EPSDT is a routine schedule of well-child visits, also referred to as screenings, that states must establish.” This article explains the EPSDT mandates and what is involved in such features as determining medical necessity, ensuring access to care, information requirements, and strategies to ensure EPSDT compliance. Resources for further reading are also provided.

This issue concludes with one of our most popular features, a Readers’ Corner summary and analysis of a recent article from a professional journal. In this case, the article is entitled “Challenges in Pediatric Home-Based Hospice and Palliative Care: A Case Series,” and it was published in the ***Journal of Pain and Symptom Management*** in October of this year. Dr. Toce explains who will benefit from the information in this article, what are the main benefits and challenges to this type of home care as the article describes them, where and how this care can be improved, and where to go from here.

Introducing The National Alliance for Care at Home: Shaping The Future Together

Steve Landers, MD, MPH
Chief Executive Officer
National Alliance for Care at Home

Why the Alliance?

The National Association for Home Care & Hospice and the National Hospice and Palliative Care Organization have come together to form a new organization: the National Alliance for Care at Home. The Alliance brings nearly 90 years of combined organizational operating experience—and complementary capabilities—to create a new, stronger organization to lead into the future.

Our mission is to serve as the leading authority in transforming care in the home. We are an inclusive thought leader, advocate, educator, and convener, serving as the unifying voice for those providing and receiving healthcare through all stages of life. We envision an America where everyone has access to the highest quality, person-centered healthcare wherever they call home.

The care at home community—including providers of home care, home health, hospice, Medicaid HCBS, and pediatric care—is evolving, and the national organizations representing this community are evolving too, anticipating the resources, advocacy, and support providers nationwide will need. Based on months of exploration and consultation with members, NAHC and NHPCO formed the Alliance to offer members a stronger partner to support providers by:

- Representing the community in DC with a stronger voice representing the continuum of care
- Delivering an expanded suite of resources to help you grow your organization
- Connecting you and your colleagues with peers across the care continuum
- Providing expert-led industry regulatory guidance
- Supporting and promoting the highest quality standards for care
- Raising consumer awareness about the value of home care, home health, hospice care, Medicaid HCBS, pediatric care, and advance care planning\

Coming together means we are better positioned to help you prepare for what's to come, and to ensure our larger, collective voice is heard on the issues that matter most.

Our Future Together

I am humbled to be the leader entrusted to bring this future vision to fruition. My roots in this community are in patient care. Early in my medical career, I raised my hand at the opportunity to start programs at Case Western Reserve and Cleveland Clinic offering medical house calls. Health systems and hospitals were not really delivering care in homes at the time, and I was interested in addressing an unmet need and seeing what I might learn working outside of the walls of the hospital and clinic.

Most of my patients had low levels of mobility. I got to meet them on their turf, see where and how they lived, and meet their families and caregivers. Those connections teach you a lot about what patients really need, and how we can best support them and their loved ones. Those experiences shaped my views on how care is delivered; I started to see the need to better connect home care and hospice to the broader healthcare system and medical community. I loved making a difference in each patient's life as a physician, but I knew that to truly improve patient care at scale, I would need to understand the intersection of clinical work, health policy, and systems of care. That's what led me toward public health and fueled my passion for influencing federal and state policy to improve healthcare delivery to vulnerable patients.

I have been fortunate to have opportunities to serve in many ways, from my time at the Cleveland Clinic to my role as President & CEO of VNA Health Group in New Jersey. It has been my job to focus on how effective systems and policy can ensure the delivery of high-quality care. And I have been an advocate at the local, state, and federal level for regulations and policies that support good health systems and high-quality care.

The opportunity before us as the Alliance is equal parts exciting, impactful, and challenging. I am honored to support our community as we chart a new path forward.

Pediatric Care in the Alliance

Pediatric care plays a critical role in our imagined future of supportive care and care in the home. Currently, through concurrent care, many pediatric patients utilize the range of the continuum of care from palliative services, home care, and hospice services.

The Alliance will serve as a stronger and more efficient partner so patients and providers can achieve their goals. Both NHPCO and NAHC have been committed to supporting pediatric patients along with their families, communities, and providers through resources, advocacy, and education for many years. The Alliance will continue and build upon this work.

This issue of the Pediatric e-Journal is a small first step of many steps we will take to integrate and build upon the pediatric work of both legacy organizations. You can continue to expect the excellence you've come to expect from the Pediatric e-Journal and other Alliance pediatric advocacy, resources, and education as we move forward together.

A Journey of Love and Care for Riley

Amanda Gilmore,
Riley's mother
agilmore5190@gmail.com

My firstborn daughter, Riley Marie, was born on May 6, 2020, with a life-limiting diagnosis: Trisomy 13. She lived for 117 precious days on earth, but will live in our hearts forever.

Many challenges with Trisomy 13 are possible, and it's important to know that Trisomy 13 is a spectrum, and because of that, the care for each baby should be specific to their own needs and reflective of their family's goals. We decided to follow Riley's lead and to make care decisions based on what we felt was best for her.

While there's a lot that can be discovered through an ultrasound, there's no way of truly knowing how a baby will fare until they're born. We spent the second half of my pregnancy learning more about Riley through fetal echocardiograms, an MRI, and regular check-ups with the perinatologist. From these appointments, we learned about the challenges she would likely face after birth and what our options were for her care. The doctors who got to know Riley during pregnancy often said that she was surprising them; from what they could see, there were no immediate life-threatening concerns. This brought us so much hope through a time filled with immense anticipatory grief. We knew her time would be limited, but we prayed for the gift of any time together and started planning for her life.

My husband, Jeff, and I discussed our wishes for her, no matter the outcome. We worked with a perinatal hospice organization, Be Not Afraid, which helped us outline the care we wanted for her if she were to be born alive, the support we wanted if she were to come home with us, and even what we desired if she died shortly after birth. I never imagined that my birth plan would also include a plan for her death, but we knew we had to communicate that we understood the severity of what could happen. It helped us feel like her medical team knew we were aware of the challenges ahead.

Riley was born breathing and crying on her own via emergency c-section. She was able to come to my recovery room in the mother/baby unit for a few hours until she was transferred to the NICU for apnea. Our goal was to stabilize her so that we could bring her home. There were times in the initial days when it felt like there was a rush to get her home since that was part of our goal, but we reiterated that we didn't want to rush her home just for her to die. We felt that if we were patient and gave her a little more support, she would be able to come home for longer.

While we were in the NICU, we met with the palliative care doctor. We didn't know what to expect from any meeting, as this was all so new to us. She was the perfect blend of what we needed—compassion for what we were going through while acknowledging the reality of our situation. For each goal we had, she helped us define the steps we needed to accomplish to reach those goals. Together, we also discussed our more personal goals for her life—things we wanted her to experience.

This felt even more far-fetched because everything I thought of existed in another life that didn't feel weighed down by what we were experiencing. We talked about wanting her to meet her family and some friends and to experience being outside. Basic things that felt like big asks. We all had tears in our eyes during this conversation, but the doctor said, "We must always have hope." Something struck us after this meeting, and we realized she was right: it was time to make some memories.

We watched movies together, played music for her, read books, and, with the help of the NICU staff, took her outside. During this time, Riley did beautifully as we weaned her off the ventilator and transitioned her to supplemental oxygen through a nasal cannula. We especially loved that we got to see more of her face. With this improvement, among others, we started making plans to bring Riley home on concurrent hospice care. After three weeks in the NICU, Riley was home.

It's natural for any parent to be nervous about bringing their baby home from the hospital, but it's a whole new ballgame when you're meeting a hospice nurse at home and ensuring that all the appropriate medical equipment has been delivered. Her equipment included an oxygen concentrator, feeding machine, pulse oximeter, suction machine, and nebulizer. We learned how to take care of all her needs while still in the NICU, and we had the support of her nurse once we were home. At the beginning of our days together at home, her nurse came by to check in every other day. Over time, we got the hang of things and were able to reduce her visits to about twice a week. Having the support of our nurse was exactly what we needed.

During Riley's time at home, we tried to make life as normal as possible. We took her on walks in our neighborhood every day, which felt like a huge deal knowing we hoped for her to be outside, even just once. We had family and friends come to meet her through our sliding glass door (she was born in the early pandemic days), and as we grew comfortable, we enjoyed some visits in our backyard. She was well-known for her cute donut hat, unicorn pacifier, love of Taylor Swift music, smiling with her eyes, and being the coziest-looking baby anyone had ever seen.

As we became more comfortable with our routine, we started to think about other experiences we'd like her to have. We worked up the courage to take her to our family cabin in Twain Harte, CA, for two days. While we were extremely nervous to leave the comfort of our home and not have our hospital nearby, those were actually the days she was most content. She felt the fresh mountain air and how relaxing it was to lie by the lake, and she was as happy as could be. I'll never forget when we arrived and set up her feeding machine outside on a tree stump. I posted a photo on Instagram, and a friend of a friend who is a palliative care nurse responded, "THIS is the epitome of palliative care and quality of life! Good job, mama." I took a screenshot because it meant the world to me and was one of the best compliments I've ever received in motherhood. This trip made me think back to that meeting we had about our goals—a meeting where I could hardly respond because everything felt so unrealistic and unfair. This trip was on my mental list, and taking her there felt like we were living out my wildest dreams.

After enjoying experiences we thought could never be in the cards for us, we started to believe we were in it for the long haul. During our journey, we connected with many other families over social media and saw kids living for months and years, thinking that could be us, too. We didn't want to get ahead of ourselves, but it felt that way. We had our fair share of medical concerns and scares—I never want to undermine that—but I don't often think those things define Riley, and I like to keep her privacy regarding some of that.

As we navigated through some of our concerns, we always found comfort in talking things through with her nurse. There were times, at first, when I felt a little frustrated because I would ask if something could potentially be happening, and her response was, "That doesn't happen with babies…" I would then share, "…but that does happen with babies who have her diagnosis." I showed her examples of babies living with Trisomy 13 (and a similar diagnosis, Trisomy 18) who were experiencing similar symptoms. She was amazed to see that I was part of a network of parents advocating for their babies, because the general assumption is that these babies don't live; but the truth is, some do, with proper care. Our conversations shifted after that. Instead of "That doesn't happen…", it became, "You know more than me about this. Let me know what you think this could be, and I'll help you navigate to find out." She provided her medical expertise to help us problem-solve, and we worked well together. I'll never forget the day I told her that I thought Riley had been doing so well. She corrected me, saying, "She's doing amazing! Remember when your goal was to meet her and hold her? That was your number one goal. Now, look at her!" She was so proud of "Miss Riley," as she called her.

As Riley continued to do well, we reconnected with her palliative care doctor to form new goals. She helped point us toward which specialists to seek out and when to consider different therapies, among other things. It was a real blessing having her to guide us in this way.

Although things had been very positive for quite some time, we began to see new symptoms and knew we needed to consult specialists to find the best form of care. Some days felt more normal, while others became very hard, very quickly. Then one night, Riley became gray and unresponsive. With some stimulation, she slowly came back to us, and we had a gut feeling that we were starting to see the end. She experienced two other similar episodes the following day.

Knowing what to do in that moment was incredibly difficult. It felt as though there was something wrong with me as a mother because my instincts weren't urging me to get up and go to the hospital. I knew that if we went to the hospital, we'd be separated as a family due to COVID-19 protocols. I was terrified of Riley dying in the waiting room or in the car on the way there, and I was anxious about where to begin in sharing her medical history with staff who didn't know anything about her. After discussing it with my husband and her hospice nurse, we decided to stay home. This aligned with our goals for her life, and we wanted her to feel comfort and love. The next day, we invited all her grandparents over to see her, just in case the end was near. We really didn't know what to expect but felt they should come. We spoke with her nurse over the phone (she was out of town visiting her own family on hospice), and she said the morphine we had on hand could provide some comfort. It was excruciatingly hard to administer morphine to my own daughter, but we knew it was the right thing to do. I'll never forget when Riley squeezed my hand afterward, almost as if to say, "Thank you."

Riley's grandparents all arrived around the same time (which we hadn't expected; we had just mentioned they could come sometime that day). Within about five minutes of their arrival, Riley took her last breath. We cried, prayed, and, to my surprise, laughed as we shared beautiful memories of her. I'm so glad we decided to stay home. Riley not only had a beautiful life, but a beautiful death, too.

Hospice came and confirmed what we already knew. We asked if we could keep her body with us a bit longer, and they were very supportive. We gave her a final bath and chose a cozy outfit. Family members who had never held her before due to precautions finally had the chance to do so. It was freeing to walk around with her unattached to any tubes or machines, yet at the same time, we appreciated the time those accessories had given us. Our priest visited that day and said it best: "Riley came here on a mission to teach us all about love, and she more than accomplished that in her short time on earth." Jeff and I admired her beauty for as long as we could until we knew it was time to call the funeral home. Once they arrived, our journey of life after loss began.

I have so much more I could say about our journey, as it will never truly end. For this article, I will say that I'm grateful for the decisions we made for Riley's life. There are times when I miss her deeply, and I feel guilty for not doing more or wishing for a different outcome. But in the end, I know that if I were to do it again, we'd make the same decisions. They were right for her. Our time together was short, but it was beautiful and incredibly meaningful.

Our relationship with our hospice/palliative care team continued even after Riley passed. We reconnected with Riley's nurse, who reiterated how amazing it was that Riley exceeded all our goals. She was great at helping us celebrate what we had together while also fully acknowledging our unbearable loss. Her palliative care doctor also visited and said, "You gave Riley the best life she could have had… and she knows that." We're forever grateful for their support and consider them part of our family.

I would be remiss if I didn't share that every family's story with a Trisomy 13/18 diagnosis is different. Some families choose full interventions, and I believe those decisions are made out of love. Some families choose comfort care, and I believe those decisions are also made out of love. Some families, like ours, have had wonderful experiences with palliative/hospice care, while others have had the opposite experience. I've connected with dozens of families over social media, and each story is beautiful. No two stories are the same. Each of our babies' lives is meaningful. It's an experience I would have never initially chosen, but it's also one I would never change. Riley will always be worth it. We love you forever, sweet Riley.

Top Seven Things No One Taught Me About Caring for My Child at Home: A collaborative parent perspective article led by national parent advocate

Dannell Shu,
Levi's mother
Dannell.Shu@RedBirdTime.com

This article was generated from a collaborative conversation and in-depth survey responses with eleven parents of seventeen HopeKids** with extensive medical complexities. Dannell Shu compiled their shared wisdom and insights to articulate these seven critical gaps. 54% of these parents are actively caring for their HopeKid, 27% are bereaved, 18% are both. Their wisdom represents a combined experience of 95 years.

1. Anticipatory guidance from clinicians and peers would have saved me and my child from additional heartache and trauma.

If only it had been available, but it wasn't and years later, still isn't. Across the board, in every domain, parents cited anticipatory guidance as the number one missing element from their ability to successfully care for their child at home. From specific medical skills, to problem solving strategies, to understanding their child's diagnosis more fully, to what constitutes an emergency, to operating equipment, to establishing routines, to accessing resources, to engaging in the community—the list goes on and on. Some parents are able to access informal peer support through social media. Even for those who do, it can take years to develop the skills to discern what advice is best for their child. As their child ages, the needs and challenges shift. Parents easily described multiple situations where physical pain, heartache, and trauma could have been avoided. Not having trusted people who offer guidance, education, support, and reassurance was and continues to be a significant challenge.

> *"It felt like I was climbing Mount Everest without training or guidance while the professionals were discouraging me."*
>
> *"I needed a guide / navigator with lived experience to help me and give me tips."*

2. The medical education I received at the hospital before discharge was less than basic.

From the initial hospital discharge after diagnosis to subsequent discharges, parents have found the medical education they received didn't fully cover the basics of what was needed to care for their child at home.

For example, it is one thing to know how to operate a feeding pump and connect it to a G/J tube. It is another thing to have the knowledge and skills to problem solve through challenges, know how to vent, when to pivot to bolus/pause, keep the belly skin healthy, manage reflux/vomiting, handle an unexpected tube removal, and do nutritional mathematical gymnastics.

Even the basics aren't enough. Parents described how advanced and nuanced medical skills are needed to identify needs and provide ICU level care at home. They desired access to ongoing training, online resources, and peer mentorship. In the feeding pump example, helpful resources include: Pediatric Home Services' how-to educational videos, Courageous Parents Network's parent stories on feeding tubes, and NeuroJourney's GI guidance.

> ***"There is so much I was never taught."***
>
> ***"I can remember when the first shipment of medical supplies came to our home. I had no idea what was what. It was my child's home care nurse who spent hours with me going through every single medical supply and providing a thorough explanation, which helped immensely."***

3. Advocacy and effective communication skills are essential.

When asked if their today-self could teach their earlier-self an interpersonal skill, this was the parent's number one response. Parents report these skills open the doors to critical information, increase access to help, and connect parents with resources—for their child and for themselves. This includes developing the courage to ask clinicians and home care staff difficult questions. Respectfully and confidently pursuing concerns they have about their child, even when they aren't believed. Learning how to engage in collaborative teamwork with diplomacy. Asking for reassurance and setting healthy boundaries.

Parents reported not having established pathways for learning these skills. They learned informally through relationships with other parents and continuous trial and error.

> ***"I didn't know what to ask until something bad happened."***
>
> ***"These were the skills that were hard earned and hard learned."***

4. My home will become a 24/7 ICU, a business start-up, a training center, and an innovation lab.

People and systems are essential in each of these. Beyond medical specialists, parents develop extensive relationships with insurance companies, state/county agencies, medical suppliers, durable medical equipment companies, schools, integrative medicine providers, and various therapists. For families who have access to funding for home care staff, they take on all the human resource responsibilities of a business: staffing, hiring, training, managing, scheduling, firing, and turnover of staff.

Meanwhile home becomes a public space and privacy at all hours is lost. Parents are always on call and often carry the burden of sustaining hours of care spanning far beyond what medical residents and clinicians endure.

Many parents reported struggling to set up needed organizational systems for managing medical supplies, sanitation, storage, preparing for travel, hospital stays, and emergencies. Several described how a significant amount of stress was relieved when they set up dynamic tools for clustering cares and medications to optimize their child's daily rhythms. Those with home care staff needed the additional layer of being able to communicate these rhythms while accounting for real-time adjustments.

With every age and stage of their child's life being unique, parents have found innovation to be essential in caring for their child. Without anticipatory guidance, trial and error have been their main teachers.

> ***"I had none of the skills it takes to manage a small company, which ended up being a very large company. I felt so overwhelmed. I wanted to run, far away."***
>
> ***"I felt a lot of pressure with so many people in and out of my home."***
>
> ***"How to give myself permission to be seen (in my home with others present) in all my messiness and carve out privacy was something that took me years."***

5. In the hospital, my child lives in a bed in one room. At home we have many rooms, most don't have beds.

Families shared when they initially brought their child home from the hospital they unknowingly replicated the same scenario at home—their child in a bed in one room. Meanwhile, family life happens everywhere in the home. As convenient as it was to have the child and all of their medical equipment in one location, it also meant the child was isolated from everyday family rhythms. It took a long time, months/years, for parents to innovate another way. One example involved creating a rolling medical cart for keeping essential supplies, medications, and equipment close by while in other rooms of the home.

Related to this, parents expressed the need for training on how to safely transition and position their child in a non-bed setting. For children with limited self-mobility, parents often don't receive physical therapy in hospital/clinic settings that addresses these needs. Parents of young children to teens identified the need for improving their own body mechanics when moving their child to prevent injury and maintain their own physical health.

> ***"Transporting a child connected to machines and tubes around a house can be tricky, especially if your house is not set-up for it."***
>
> ***"A hurt (injured) parent is not able to provide adequate and safe care for children with special needs. We have to stay healthy and physically well in order to continue to physically care for our child, young to hopefully when they are older, if we are all lucky."***

6. Hospitals are fully staffed, my ICU-home never will be.

A majority of the parents spend more than 40 hours per week managing staffing at home. From recruiting, to training, to scheduling and rescheduling—this is its own full time job. Even with all this time and effort, the number of staffed hours is minimal compared to the child's 24/7 care needs. At best, some families find one or two people who are willing to dedicate months/years of sustained care, usually at pay well below their skill level. Families, including siblings, are daily carrying the burden of care.

> ***"No nursing staff, no family to help. She can't go to daycare and babysitters are too scared to help a medically complex child."***
>
> ***"We had 1 nurse that was solid and did her job dutifully for 5 years. Everyone else was bad at best. We have been robbed and threatened by nurses. It's insane."***

7. Chaos and sustained uncertainty will become the norm. Navigating the emotional terrain well requires advanced skills and self-compassion.

Parenting a child with medical complexities is an emotionally treacherous experience. Opposing emotions are close neighbors within their hearts and bodies. The diagnosis of uncertainty never departs as many parents juggle the complexities of caring for their child with the reality of death hoovering in the background.

Maintaining one's own emotional stability can be a steep learning curve for parents. It is easy to go into a panic when your child removes their G-tube or the oximeter alarms are blaring. Learning to ride the waves of emotions and cultivating an inner calm when the unexpected happens improves the trajectory of what comes next—for the child and the parent. Being emotionally flexible without being detached is also helpful. Parents reported how the responsibility to do well by their child can easily overshadow their own need for self-compassion.

> ***"Before, I would panic and now I've learned it's okay. We've done this before, we are confident and this is going to be ok. Breathe and get it done."***
>
> ***"I am managing an impossible situation to the best of my ability."***

Contributing parents:

Kaitin Benedict, mother of Roman. A funny and courageous child.

Andi Elliott, mother of Charlotte. A happy forever-baby.

Amy Fields, mother of Cary Lynn and Marvin. Siblings with strength.

Katie Gerson, mother of Callie. A smiley, stubborn five year old.

Julie Martindale, mother of Aaron, McKenna, Evan, Issac, Elijah, and Maisey. A courageous bunch of spirited teachers.

Tiffany Patana, mother of Cara. A silly sassy toddler.

Nancy Rash, mother of Willa Faith. A loving and brave six year old.

Cristina Renteria, mother of Atlas. A funny and resilient three year old.

Lori Wells, mother of Caden. A fifteen year old with the determination of a fighter.

Jinny Zroka, mother of Zaccheaus. A brave seven year old who loves all people.

Dannell Shu, mother of Levi. A child who mastered patience. Dannell serves on the National Coalition for Hospice and Palliative Care's Pediatric Division. Through RedBird she offers clinician education, consulting, and resource innovation for improving pediatric healthcare and clinician wellness. www.nationalcoalitionhpc.org/about-the-coalition/pediatric-division

***** Special thanks to HopeKids.org for creating and supporting community among our families. HopeKids is a national organization dedicated to restoring hope and transforming the lives of children with life-threatening medical conditions. Through state chapters, they provide ongoing events and unique community building opportunities for children and their families.***

A Family's Financial Fairytale: What It Teaches Us About Paying Parent Caregivers and What is Possible

Dannell Shu,
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After a child is born/diagnosed with medical complexities and requires ICU-level care at home, a significant amount of burden is placed upon the parent(s) to provide this care. The patchwork of financial resources (health insurance, Medicaid, waivers, grants, programs) available to each child varies greatly by state, and many times by county. How the pieces do/don't fit together increases the burdens of care and can financially ruin a family for decades.

The patchwork available to my family, living in Minnesota, is a fairy tale to most families. Even those who live in the same county don't automatically have the same access to this fairy tale. So much of it depends on the foundation that was laid, the people you encounter, and barriers they help you navigate.

In this article you will find a series of snapshots describing how our fairytale unfolded. As you read through, I encourage you to consider what part of this can you help current/future families with? How does your clinician role give you the opportunity to be a game-changer, a fairytale-maker?

We were completely wrong.

In 2009, while pregnant with my first child, my husband and I had naively assumed we could easily juggle childcare and our jobs. Layered into this was a presumption our child would be born healthy and grow to outlive us. That's not how our story went. Levi was born with severe HIE, the initial prognosis was hours to days, and he lived just beyond his seventh birthday.

We narrowly missed being financially shattered.

During my prenatal care clinic visits, the provider was intentional about helping pregnant women get connected to health insurance for themselves and their child. Due to my job not offering insurance, I was enrolled in Medical Assistance (Minnesota's Medicaid program). All of my pregnancy and birth-related health care costs were fully covered. When Levi landed in the NICU this insurance was already in place to fully cover his rapidly accruing costs. A NICU Social Worker invested in helping Levi apply for a disability certification. The infrastructure of MA and certification created a pathway for the medical and therapeutic expenses related to Levi's ICU-level newborn needs to be paid in full, without the mess of copays and out of pocket premiums.

I was unable to return to work.

When Levi came home from the NICU at three weeks of age with great uncertainty about the duration of his life, my husband and I became an ICU-home staff of two. My time was devoted to caring for Levi and running the "business" of his medical needs. There wasn't an ounce of time to return to work in any form. And still there were household bills to pay. My husband expanded his work hours to include two jobs plus a side hustle.

We were stretched thin.

In the coming years Levi's care team slowly expanded to include paid Personal Care Assistants (PCA) and nurses, but it wasn't enough help. At best we had night nursing three nights a week. My husband and I split the remaining four nights a week. Searching for and hiring new staff was a continuous process. I was always the default substitute when a staff person got sick or could not make it. The difficulties escalated as we welcomed a second (healthy) child into our family when Levi was 2 ½ years old. We were in an unsustainable situation; physically, emotionally, and financially.

Game Changer #1 - a 2nd layer of insurance

With the encouragement of fellow parents, I advocated for Levi to apply for a Community Alternative Care (CAC) Waiver. This MN state-based waiver, established in 1985, recognized Levi's needs as being hospital-level care and opened the door to additional financial resources to support his living at home. It was like having a second full coverage health insurance plan. Most anything medically necessary MA would not cover the CAC waiver did, 100%. This further reduced the financial burden upon our family and expanded the kinds of resources we could access for Levi's changing needs.

Game Changer #2 - parent-designed budgets

The CAC Waiver opened the door for me to advocate for Levi to have a Consumer-Directed Community Supports (CDCS) community support plan. This innovative state-based program, established in 2001, provided us with the opportunity to create a parent-designed budget for the goods and services Levi needed, based on the state portion of his CAC waiver funds. Each year we determined his greatest needs, established goals, navigated CDCS restrictions, and designed a budget to reflect those goals. The CDCS allowed for a much wider definition of "covered" goods and services than MA or the direct CAC waiver. Finally, Levi's actual needs within the context of our home and family were at the center of his resource utilization. We could be significantly more proactive in anticipating and supporting his needs.

Game Changer #3 - financial recognition as parent-caregivers

Within Levi's CDCS annual budget we were allowed to be paid as parent-caregivers as PCAs for him. At the time (2014), one parent could be paid up to 40 hours a week at about $16/hour. Federal recognition exempted this income from being taxed. The opportunity to be paid for a small portion of the hours we invested into caring for Levi allowed my husband to end his second job and become a more present father to both our sons. For a father of a child with a life-limiting condition, time is precious.

What Matters Most

Thanks to MA+CAC+CDCS I did not waste countless hours appealing insurance denials for Levi's needs. Generally, what one didn't cover the other did. We did not waste a dollar on copays or deductibles. His needs were covered 100%. I could focus my efforts on caring for Levi and managing the "business" of his care.

Having these financial resources in place allowed us the ability to focus Levi's resource utilization on his highest needs. Levi participated in therapies and intensives that produced the greatest impact. This resulted in a higher quality of life. We purchased equipment that allowed for him to be in nature, regardless of weather. He got to be among children and engage with nature in meaningful ways. We could improve the pay rates for our staff, resulting in higher quality care. Having a robust staff and parent pay allowed us the flexibility to schedule regular respite weekends with my husband. These 2-day reprieves were deeply restorative to our marriage and our capacity to continue caring for Levi with sincere joy. None of this would have been possible with just MA.

As it turned out, after the first CDCS budget was approved, we only had 26 more months with Levi until his death. In those months we spent more quality time together as a family because of the parent-directed budget and parent pay support. My husband directly credits these resources as critical to his ability to actively care for Levi (he was on the care schedule!) and the depth of his relationship with our sons.

Additional Notes

Parent Pay

During COVID and under the peace time emergency, both parents were allowed to work as PCAs and receive parent pay for up to 40 hours/week. This was available to families whose child was on a waiver, even if they were not on the CDCS program. This ended when the peace time emergence ended.

In 2023, Minnesota passed significant legislation to restore the two-parent pay option. After approval by CMS this was approved and went into effect early 2024. It allows for children on the CDCS program to include parent pay for 40 hours/week for both parents at $22/hour. The hourly rate can be increased when a parent completes additional training. A single parent is allowed 40 hours/week plus 20 hours overtime/week.

This same legislation increased PCA pay and PCA staffing agency rates. Siblings 14 years + continue to be allowed to be paid as PCAs. This is of critical note because sibling caregivers are unacknowledged as being a valuable part of the care team. All of the families I personally know with paid sibling caregivers are careful to allow the sibling to decide if and when to formally step into this role, and the greatest flexibility in setting and changing their care schedules.

The TEFRA Doorway

In Minnesota, if a family with a child certified as disabled is not able to access MA, because of the income restrictions, TEFRA provides a doorway to access MA and the waiver system. This is a unique innovation advocated for by parents in 1982. TEFRA is short for the Tax Equity and Fiscal Responsibility Act, the federal law that sets the rules for this option. Prior to the 2023 legislation, families paid a monthly fee, based on their income, to access the TEFRA option. These fees were known to be exorbitant, resulting in significant and inequitable access barriers. The 2023 legislation removed the TEFRA fees.

Critical Parent Advocacy

It is important to note, Minnesota parents have been essential to the legislative actions and programs designed to financially support children with medical complexities living at home, with their families, and participating in community life. Their tireless work alongside legislators continues to improve access to valuable financial resources.

What Minnesota has been doing since the 1980s to create a more sustainable financial infrastructure for families can be replicated.

Dannell Shu, mother of Levi. She lives in Minnesota and is thankful to the generations of parent advocates and clinicians who stepped forward to envision a better tomorrow and pursue legislative changes. She serves on the National Coalition for Hospice and Palliative Care's Pediatric Division. Through RedBird she builds upon the foundation she "inherited" to create lasting change for families and clinicians.

The Need for a Paid Parent Caregiver Program

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Hearing the words, "I'm sorry, your child has a rare disease, and unfortunately, it is terminal," is devastating words no parent ever wants to hear. This happened to my family when my daughter, Lily, was diagnosed with Juvenile Tay-Sachs disease at age 7½. In an instant, our lives changed forever. We realized that our hopes and dreams we had for our little girl were no longer going to happen, and everything we had envisioned for her future was suddenly out of reach.

Within just six months of that fateful day, I found myself taking on multiple roles—researcher, caregiver, appointment setter, and more—as I watched my child grow weaker. I had to quickly master the use of complex medical equipment like cough assist machines, suction devices, CPT vests, adaptive strollers, and wheelchairs. New terms like DME (Durable Medical Equipment) and insurance codes became part of my everyday life as I navigated this complex and often overwhelming journey.

Caring for a child with complex medical needs is a 24/7 responsibility that brings immense financial and emotional challenges to families like mine. Many families are forced to transition from two incomes to one to provide the necessary care, while single parents face the seemingly impossible task of balancing caregiving and employment to meet basic needs. For those fortunate enough to be prescribed private duty nursing care, finding and retaining reliable in-home nurses is a constant struggle due to a severe nursing shortage. Even when staffed nursing care is available, a parent's presence is still required for every appointment and therapy session, making it nearly impossible to maintain steady employment.

My daughter, Lily, is now 11 years old. Since her diagnosis 3.5 years ago, it has been incredibly difficult as a single mom to care for her 24/7 with minimal nursing coverage while also raising her sister and trying to provide for our family. The Medicaid waiver program in Florida, which is meant to provide assistance for families with children who have serious medical needs, has a waitlist that exceeds 10 years, with no fast-tracking even for those with terminal diagnoses. It took me 2.5 years of relentless advocating before finally receiving some assistance, and even then, it is not enough.

For the past several years, I have been part of a parent advocacy group here in Florida, fighting for the establishment of a paid parent caregiver program. Such programs are not only essential—they can be life-changing. They provide financial stability for families and allow parents to deliver the best possible care for their children. After all, no one knows a child's needs better than their own parent. Research has shown, and my experience confirms, that children thrive when cared for by a parent who is deeply attuned to their needs. In fact, my daughter's doctors believe that Lily is doing as well as she is because I am her primary caregiver.

Implementing a paid parent caregiver program would have far-reaching benefits. It would help alleviate the nursing shortage by reducing reliance on outside nursing care and provide a cost-effective solution for the state. This model of care ensures that children receive the best possible support, and it allows parents to dedicate themselves to what truly matters: being present for their child.

For families like mine, having a paid parent caregiver program would mean more than financial support—it would mean quality time with our children, less stress, and the ability to focus on providing the love, care, and attention they deserve. I firmly believe that no parent should be forced to choose between being there for their child and earning a living, especially when they are fully capable of providing the best care themselves, at a fraction of the cost to the state.

This is why I advocate so passionately for a paid parent caregiver program. It is a solution that would uplift families, ensure children receive the best care possible, and offer an approach that is both compassionate and fiscally responsible. By investing in programs like these, we invest in our children, our families, and our communities. Together, we can make a difference and offer a lifeline to those who need it most.

Private Duty Nursing and Pediatric Hospice Care

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I am the Omaha Nebraska Branch Administrator for Pediatric Home Service (PHS). My branch office provides private duty nursing (PDN) services for medically complex pediatrics. This means that I play the ultimate game of matchmaker between nurses and families, as well as the support for everything and everyone in between. When I get the chance to explain what I do, I simply say “I have a ton of kiddos with trach/vent/gastrostomy tubes/seizure/hospice/genetic diagnoses and needs that require what I like to call a super nurse, and I get to find nurses that want to be a ***super nurse***”. While that is a significantly simplified explanation of my role, we all know it is the most realistic one there is.

My Connection to Care at Home

Growing up in an incredibly rural location, I was first exposed to home care in a different style than most. I was raised in a medically minded household. My mom often provided private services to people in our area where no company would go. She even had an emergency bag that remained by the door, just in case. Neighbors would call our house in an emergency; my parents would then call 911 to give directions as they walked out the door. My parents, who are former police, firefighters, and EMT, provided support while additional backup arrived.

Being the youngest child, I was always following on my mom’s coattails, so my “home care” career truly began around the age of 6. I took on my first special needs nannying position at the age of 12, caring for a neighbor’s child who was born with Rett Syndrome. Cares included medication administration, g-tube cares, seizure interventions, and coordinating with the child’s parents, doctors, and pharmacies. This was certainly not a normal job for a 12-year-old, but it was a job that cemented my love for this specialty. While in college for my nursing degree, I took on a few more special needs nannying positions and immersed myself in the world of medically complex pediatrics.

These experiences showed me just how important it was to keep kids home with their families, where they belong. I started in the pediatric PDN line of care as a nurse in early May of 2021. Looking for a “fun” side job in addition to my full-time role, I happened upon an ad for PHS via social media. I quickly fell in love with the job as a field nurse and was offered an opportunity as an RN supervisor in the office by October that same year. As fate would have it, after some quick and unexpected changes, I found myself as the Omaha Branch Administrator of Pediatric Home Service by April of 2022.

A Differentiated Service Line

Private duty nursing is often seen as the same as home health. While the two are in the same industry, they are vastly different from one another. So much so that we often work in tandem with home health companies, as well as hospice companies, because we all provide different types of care to our clients at home. Private duty nurses truly define what it means to be a super-nurse. Our nurses work night, day, and weekend shifts, all to ensure their patient stays alive. They single-handedly work through emergency events without a code team or floor leads to support them. They work as a certified nurse assistant, caseworker, advocate, respiratory therapist, infusion nurse, housekeeper, physical therapist, occupational therapist, speech therapist, educator, school paraeducator, friend, supporter, confidant, and above all, as a nurse to make sure that parents come home and wake up to a happy and stable kiddo. It is a niche career that very few are lucky enough to experience, but we sure do enjoy helping as many people experience it as possible.

When nurses come to us, it is not usually for the money, or the adrenaline, or the title. They come to us because they want to make a difference in the lives of their patients, every single day. They want to be a part of that experience. They want to see the same kiddo that they first helped to walk in a walker for the first time; play in their special needs sports team. They want to see the kiddo that they spent countless hours singing to become a member of the band or choir. They want to see their kiddo who has a terminal diagnosis make every day amazing and be there for them and the family when that kiddo finally gets the peace of their last breath. You could say we specialize in super nursing, but our patient families tell us we do so much more than that.

When asked by Endless Journey (EJ) Hospice to write an article sharing the home care nursing perspective for this e-Journal I began thinking of all the ways I could use this platform. I could speak about the challenging decisions made at the state level, the lack of understanding around the needs for pediatric home nursing, the missing support for medically complex patients when transitioning from the hospital into the community, the need for investment from the state into parent education ahead of discharge, and the list could go on. However, there is one thing that all these topics have in common, and that is an opportunity to improve the system, together. As healthcare professionals we can collaborate to find solutions that make life easier, better, safer and more effective for the kids we support.

Collaboration Between Private Duty Nursing and Hospice

One of the first clients we collaborated on with Endless Journey Hospice was a little girl who lived in a rural community and had been on our recruitment list for more than a year. She went to the hospital for a minor heart procedure and was discharged with a newly placed tracheostomy, became ventilator-dependent, and had a new onset of severe seizure occurrences. To say the least, she left the hospital a completely different patient.

Endless Journey reached out to Pediatric Home Service and asked us to add this child to our recruitment list. Since those recruitment measures were already in place, we started talking more specifics.

- Why was this family looking for nursing? ***They needed support.***
- What hours did they want? ***Dad worked split shift overnights as a first responder, and mom just never slept, so they decided nights would be ideal.***
- What were their expectations for Private Duty Nursing services? ***Please just keep their daughter breathing.***

These questions and answers were the same as all the other children on my recruitment list. Parents of medically complex kids need hours, need support, need sleep.

When Endless Journey Hospice brought this client request to me, I recognized that this would be a patient who could open doors for others just like her. I worked to schedule a video call with my supervisor and the leadership of the family's Medicaid provider to try to work out a deal. After much information gathering, we were able to have a critical conversation with Medicaid to explain why this was a unique case and why we needed to do everything possible to get nursing support for her. She became an SCA (special case agreement) client, which means we were able to offer higher wages for nurses, and we had her staffed within a few months of the agreement. While "months" seem to be a long wait time, in the world of private duty nursing, there are families that look for nursing for YEARS, so, it was an exciting and successful outcome. WE presented our argument, WE advocated for our client, and WE succeeded in working with insurance to find a solution.

In the end, we had full-time night coverage in this child's home. It let mom sleep, let dad sleep without feeling guilty, and provided support to the other children in the home with parents who were able to be more present.

Advocate, and Advocate Hard

A few months later I received a call from one of the pediatric nurses at Endless Journey Hospice telling me that hospice services for this client have been denied. Shortly after, I received a call from my authorization team telling me that private duty nursing services were denied. The family received the same letter. The heartbreak that I heard while talking to the family was palpable. Review requests, calls, emails, follow-ups with supervisors, appeals, and arguments became the center of attention with this case. Argument of the CCCR (Concurrent Care for Children Requirement) was brought forth. The authorization department wasn't denying these services because they had it out for the family, they were just following the rules they thought they understood. They didn't know there were so many different types of nursing services and that we all provided different care. This family would have been denied nursing support and hospice services if we didn't step up to the plate to advocate and educate.

I don't share her story to build resentment toward insurance providers. They are not at fault. They are hoping to do their job as accurately as they can. I share this to rally everyone in the healthcare community to work together to support our patients. No single person has all the answers, but we can always try to find the answers, be educated, and care enough to question decisions. These families are at our mercy, and we can either choose to provide sympathy and apologize, wishing there was more support you could give, or you can advocate just as aggressively as you would advocate for your own child.

Throughout my three years in this position, I have partnered with insurance on some very interesting cases. No matter who I have talked with in the Medicaid/private insurance world, everyone is interested in helping their clients. The case workers want to know what they can do, and the authorization team wants to know the entire background on each patient. Even their supervisors want to help these kids; we just need to communicate how.

Most hospice/PDN service provider relationships I have seen are non-existent. Each is aware of the other, but there is often no communication in the trenches. We owe it to our families to change that. My team has worked at length and are still currently working with hospice companies who care for our patients to ensure that continuity of care is never risked.

Working alongside Endless Journey Hospice, we've created an editable document for referral updates to ensure we share the most accurate and up-to-date information while recruiting. This document allows us to discuss each of their pediatric patients quickly and accurately. It also ensures the assigned nurses align with the medical needs of the child and covers any customized requirements for working with this family or home. They send the updated document for possible clients, and I can help clarify if the client meets the requirements for PDN services. This simple document helps us guarantee that we are doing everything possible to get this child and their family the support they deserve, and the nurse the career they deserve.

Not all of our patients are hospice related. Many are kids who will need PDN support long-term. We have the honor of watching patients graduate from our services all the time. We are there to celebrate the decannulation, bringing balloons to the "first foods" parties when a child is cleared of NPO status, and getting to watch them graduate from school with their long-term nurse by their side. I get the opportunity to see these families and kids grow, and I beam with pride and thankfulness as I leave their house for the last time after discharge. While the outcomes may be a little different for our hospice patients, the feeling remains the same. I want to leave their house for the last time feeling nothing but pride and thankfulness. Pride that my team and cohorts did everything we could to make sure that family had the support and care they deserved. Thankfulness that the family and child are at peace, that we have selfless nurses who provide this support, and that we have people in the insurance, hospice, hospital, and complex care teams that care enough about this child and family to do everything they can to meet needs. What a truly humbling position to be given.

I could go on for pages about what we do, and what we need to change, what we should expect and press for. My original goal was to educate you all with as much information as possible, but as I started writing this article, I quickly saw a better opportunity. To encourage and motivate. You are what makes a difference to these patients and their families. You can advocate until you are blue in the face, and then you can take another breath and advocate some more. You can support these families by any means possible, even if they aren't typical routes. You can be what makes a difference to these families. So, read those articles/rules, write that appeal, schedule that call, ask those questions, make those teams that stretch across innumerable care groups. As health care professionals, we owe it to these kids to do everything we can, and we owe it to them to be one big team.

Adjusting to Care in a Home-Based Pediatric Hospice and Palliative Care Program After Working in a Hospital Setting

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Pediatric Home Care Nurse

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Pediatric Home Care Nurse

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Jennifer's Perspective as a Manager:

One of the things that I have always taken into consideration when hiring nurses for our pediatric team is where they have worked prior to applying for a position on a pediatric hospice and palliative care team. Considering the setting that has been part of their nursing career will help you as a manager know how to make sure they are supported during the transition. It may be from managing their day-to-day schedule and the adjustments that come with it, to being able to tell people that pediatric hospice and palliative care is now their area of work.

Many nurses can initially struggle with how to set up their day. Much of their time spent with the family is helping to manage the needs that have come up and not the hands-on care that they did in the hospital setting like giving medications. Providing them with a good support and examples on how to build the trusting relationship with parents who have managed their child's care over a period of a few months to years is key when setting up time for them to see other team members' interactions with the family. Even a nurse who has worked for multiple years in the field of nursing, will take time to feel comfortable with becoming a hospice nurse.

Krista's Career Journey:

When I started working with hospice on the adult side 10 years ago, I knew I had found my calling. When I was hired, I was an LPN who was hired on the Extended Care Team (ECT) working overnight. We provided symptom management for our patients so they could, hopefully, stay at home or in their nursing facility. When we didn't have a case to staff, we would help with on call. This was my first introduction to pediatric hospice.

The first pediatric call I went on, I remember the triage nurse saying, "take a breath, the patient is 5 years old." I remember being terrified. What do I do, what do I say to this patient's mother? It turned out that those answers came naturally. Support the mother in the moment and be there to assist her when she needs it.

Soon after that visit, I received my first ECT case of a 9-year-old child in his home. Since I was still very new to the peds hospice world, I approached this visit as I had done with the on-call visit. Follow the parents' lead. This overnight visit taught me to observe the family and their caregiving approach with the patient. Giving them the space to be with their child but still offering hospice presence and support when needed appeared to be the best approach.

A few years later, I became a full-time nurse on the pediatric team. Again, that fear crept back in. Could I do this every day? Could I care for a dying child as well as their family daily? I quickly learned that pediatric hospice is not all doom and gloom all the time. In peds, families often opt to continue to seek treatment and answers for their child's condition. Some of these patients can be on hospice services for months and even years.

The biggest takeaway with pediatric hospice is to listen to the patient's caregivers. They are with their child 24/7 and often their intuition is right. As a hospice nurse, we see the patient an hour a week on average. Their parents and family can see the subtle changes their child is making on a moment-by-moment basis. There are many visits during which the only interaction with the patient is during the physical assessment. A lot of visits are spent talking with the caregivers and listening to their concerns.

We build those nurse-family relationships every visit we make. They begin to gain trust in us the more we interact with them. Often the first step of that relationship is for the parents to start relying on hospice to order medications, supplies, DME, or to reach out to the doctors and to follow through with their patient concerns. Parents learn to contact hospice first for advice and symptom management where in the past taking the patient to the hospital was their priority symptom management tactic. We become the ones they turn to with questions or doubts or just someone who will listen to them.

Erica's Transition to Pediatric Hospice and Palliative Care:

Weeks before I left my position as a postpartum nurse, I told my friends and coworkers that I was leaving and taking a position as a pediatric hospice home care nurse. Everyone knows my passion for home care, but as they congratulated me most expressed that it was out of their comfort zone to do this kind of work. But they all said that they knew I'd be great at it. I smiled and said I hope so.

During my orientation period I had many questions. I like to be prepared. I have the belief that the more prepared I am, the better I am for the patients and families I work with. I have already learned that in hospice and palliative care it is unlikely to be able to be completely prepared. Every case and every family are different.

I believe like Krista that I wanted to be emotionally prepared for my patients and families. One thing that always stands out to me when someone says hospice or palliative care services is the care and compassion their loved one received.

As I started this journey, I wanted to know how not to disappoint my patients and families. Not that I'm a perfectionist, I just wanted to know how to live up to the hospice care standard. I wanted to know how to look when I went into a room and met a patient and family for the first time. Is it appropriate to smile because I'm a smiler. Yes, I still smile.

As a new hospice and palliative care nurse I've also had to help my family understand the work that I do as a pediatric hospice nurse. They worry about me and the emotional toll it might take on me. One morning during a team meeting I asked my coworkers how they explained the work they do to their family.

I received an amazing answer from one of our social workers. She explained that these children are unfortunately going to die. However, with our assistance these children and families get help navigating this transition in their life with our guidance and support. It made so much sense to me. While I don't think it will ever get easy for us, it is a wonderful way to capture the heart of what we do for children and families.

In Summary:

While we all have a different story on what led us to pediatric hospice and palliative care, we can say that we not only want to support the patient and their needs but also be present for the family as they walk the journey of care.

It is important for the nurse to feel supported in not only sharing their knowledge from previous work experiences, but also as they transition to work that allows the parent and family to have a bigger voice and role in the care that is provided. Setting up team members to be successful requires a full team approach as newer nurses learn the role of not only the nursing support, but that of the other members of the team as well. Understanding that there will be a period of adjustment will give not only managers a different view on how support the newer nurse to the team, but the rest of the team will also find ways that they can support them as well.

Boundaries in Home Healthcare

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Boundaries exist in every profession. Although in this article we refer to the nurse, this is pertinent to every member of the health care team. Professional boundaries in nursing refer to the limits that define the therapeutic relationship between nurses and patients (National Council of State Boards of Nursing, 2018). These boundaries ensure that the relationship remains focused on the patient's needs and is grounded in professionalism, respect, and ethical behavior. Nurses must maintain professional boundaries to safeguard both their own well-being and that of their patients. These boundaries play a crucial role in ensuring patient-centered care, protecting nurses from burnout and compassion fatigue, and preventing ethical dilemmas that can arise from blurred roles or inappropriate relationships with patients. This responsibility takes on new dimensions when care occurs in a home setting.

Types of Boundaries

Emotional boundaries involve striking a balance between empathy and detachment. While it is important for nurses to provide compassionate care and understand the emotional needs of their patients, they must also avoid becoming overly involved in a patient's personal life or struggles. Emotional overinvolvement can lead to issues such as over-identification with the patient, difficulty making objective decisions, or blurring the lines between professional and personal support. On the other hand, nurses must also be mindful of not becoming too emotionally detached, as this can result in cold, impersonal care that diminishes the therapeutic relationship.

Relational boundaries are also essential in preventing the nurse-patient relationship from becoming personal or social. Nurses should avoid sharing excessive personal information or developing friendships with patients, as this can lead to dual relationships, favoritism, and conflicts of interest. Time boundaries further ensure that nurses manage their schedules professionally, avoiding overextending visits or giving preferential treatment to certain patients at the expense of others. Role boundaries define the scope of a nurse's responsibilities, ensuring they remain within their professional duties and avoid taking on tasks that fall outside their role, such as offering therapy or becoming involved in personal issues unrelated to care.

Physical boundaries refer to the nurse's responsibility to engage in necessary, appropriate physical contact only when it serves a therapeutic or clinical purpose. Touch, though an integral part of nursing care, must always be contextually appropriate and respectful of the patient's personal space and dignity. Nurses must avoid any behavior that could be misinterpreted as crossing into personal or intimate territory, ensuring that physical interactions remain professional and patient-focused. This is true no matter the age of the patient and with respect to family members as well.

Lastly, ethical and legal boundaries provide the framework within which nurses must operate to protect patient safety and ensure the quality of care (Grace & Uveges, 2023; Richardson, 2022). These boundaries are informed by nursing organizations like the American Nurses Association, which set guidelines on professional conduct (Fowler, 2008). Violating these boundaries can result in legal consequences or ethical breaches, such as violating patient confidentiality or providing inappropriate care. In essence, professional boundaries in nursing serve to protect both the nurse and the patient by maintaining trust, ethical standards, and respect within the caregiving relationship.

How Nursing Boundaries Shift in Home Care Settings

The transition from clinical to home care settings presents unique challenges for nurses in maintaining professional boundaries. Unlike hospitals and clinics, home care involves entering the patient's personal space, leading to a more intimate and relaxed environment. For the purposes of this article, home care refers to both traditional home care and hospice care in the home. This shift inherently blurs the lines between the personal and professional, requiring nurses to adapt while ensuring that their boundaries remain intact. The following sections explore how home care environments complicate the management of professional boundaries, the risks associated with failing to maintain those boundaries, and strategies to ensure they are upheld.

The Unique Nature of Home Healthcare

Home healthcare differs from clinical settings in that it takes place within the patient's own environment. This more intimate and personal environment can cause professional lines to blur as nurses enter the patient's living space. The atmosphere is less formal, with fewer physical barriers separating the nurse from the personal aspects of the patient's life. Nurses may encounter personal routines, household dynamics, or family interactions that extend beyond the scope of medical care. This immersion in a patient's personal world can make it difficult to maintain the emotional and relational distance required for professional distancing.

In addition to the personal nature of the space, while caring for a pediatric patient there is often increased interaction with family members. Family members frequently play the primary role in caregiving, leading to a more collaborative or even complex dynamic. This creates additional emotional and relational challenges as nurses may find themselves mediating between the patient and family members or negotiating conflicting care preferences. The expectation to provide not only medical care but the need to also to meet emotional or social needs of a pediatric patient adds complexity to maintaining professional boundaries.

Boundary Challenges in Home Care

Several boundary challenges arise in the less formal home care setting. First, the shift to the home often results in the blurring of professional and personal lines. In a clinical environment, clear distinctions are drawn between the patient's personal life and the healthcare professional's role. In contrast, in the home, nurses may be asked to assist with non-medical tasks or engage in conversations that transcend their professional responsibilities. The relaxed atmosphere can make it harder to enforce appropriate boundaries.

The physical space also contributes to boundary issues. In home care, nurses often work in proximity to patients' personal belongings and living areas, making it challenging to maintain the same level of professional distance required in a clinical setting. Privacy concerns are heightened, as nurses navigate intimate areas like bedrooms or bathrooms, often with family members present, which may blur the lines between caregiving and personal involvement.

Moreover, home care increases the potential for emotional involvement. The longer duration and more personal nature of care often foster close relationships between nurses, patients, and their families, creating a risk of over-identification with the patient or family's emotional struggles. This emotional entanglement can compromise the nurse's ability to maintain an objective perspective on the patient's medical needs, potentially leading to compassion fatigue or burnout.

Pressure to Accommodate More Flexible Boundaries

In the home care environment, nurses are often under pressure to accommodate more flexible boundaries. Patients or family members may request extended visits, emotional support, or involvement in family matters. These requests may stem from feelings of loneliness, emotional need, or the comfort of having a trusted healthcare professional in the home. However, these requests can lead to role confusion and dependency, as the nurse may become too involved in the patient's personal life.

As the nurse visits more regularly, patients and family members can start to view them as a friend or extended family member. Invitations to join the family for coffee or lunch can feel rude to refuse. In fact, in some cultures, it is offensive to refuse these offers. Is it acceptable to cross these boundaries? The very clear answer is—it depends on the situation. If you can gracefully refuse and maintain your boundaries, perfect. "I'm so sorry, but I have to get to my next patient." If it would be offensive to refuse, accept the glass of water and say thank you.

There is a distinct difference between crossing a boundary and a boundary violation (NCSBN, 2018). When you cross a boundary (accepting the water/coffee/etc.), you know the line is there and step across it. Sometimes you do not realize you walked over the line until you already crossed it. You also immediately step back. If you violate a boundary, you willfully run across that line with no intention of crossing back over. You erase that line.

Ultimately, you do not want to upset or offend your patient or their family. However, you also do not want to do anything that will cause trouble. When in doubt, call a supervisor. As a former hospice director, I erred on the side of making my patients happy, as long as it did not get my nurses too involved with the families. We provided support and training on boundaries on a regular basis.

Consequences of Failing to Maintain Boundaries in Home Care

The emotional and relational demands of home care can lead to emotional exhaustion and burnout if boundaries are not maintained. Nurses who become overly involved in their patients' lives may struggle to separate their personal feelings from their professional duties, leading to emotional and compassion fatigue (Todaro-Franceschi, 2025). This increased emotional involvement also raises the risk of ethical breaches, such as favoritism or neglect of other patients. Moreover, the inability to maintain clear boundaries can make it difficult for nurses to achieve a healthy work-life balance, as they may feel obligated to fulfill roles that extend beyond their professional responsibilities.

For patients, a lack of boundaries can lead to over-reliance on the nurse, which may reduce the patient or family's autonomy and hinder their ability to manage their care independently. Patients may begin to see the nurse as a personal support figure rather than a healthcare professional, which can undermine the therapeutic relationship. Additionally, the blurring of professional responsibilities may erode trust if patients perceive that the nurse is overstepping or not maintaining a proper professional distance. As noted by Thompson, "Healthcare providers must make sure that the patient and family has relationships and coping mechanisms with people outside the medical team. Boundaries must only be crossed in service of the patient, balancing the therapeutic relationship that is needed." (2015, p. 464).

Strategies for Maintaining Boundaries in Home Care

To address the challenges of maintaining boundaries in home care, nurses must adopt strategies that ensure their professional integrity while protecting their emotional well-being. Healthcare organizations should provide clear policies and guidelines specific to home care settings, as well as education and training to address the unique boundary challenges of home care. One of the most effective ways to maintain boundaries is through clear communication with patients and their families. From the outset, nurses should establish expectations regarding their roles, responsibilities, and limitations. Open communication helps create mutual respect and ensures that professional norms are adhered to, preventing misunderstandings that could lead to boundary violations.

Additionally, working with other members of the health care team to help address the needs of the patient and family can also help diminish the risk of crossing boundaries. Social workers, chaplains, and child life specialists can help patients and families with social and relationship needs. Ultimately, home health providers must cultivate self-awareness, recognizing the signs of over-involvement or under-involvement. Resources such as peer support can help all team members manage the emotional strain of home care, providing a safe space to discuss challenges and reinforce healthy boundary practices (Joo et al., 2022).

Conclusion

Home healthcare and home hospice present unique challenges to maintaining professional boundaries. The intimate, informal nature of the home environment, coupled with increased interactions with family members, can lead to blurred professional lines and expectations for nurses to take on dual roles. Nurses and members of the health care team must be especially vigilant in maintaining boundaries, ensuring that they provide compassionate care while upholding their professional integrity and protecting their emotional well-being.

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Protecting Our Youngest Patients and Their Caregivers: Navigating Safety in Pediatric Home Care

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Worker safety is a critical topic across home health care, with recent attention given to managing aggressive behaviors and addressing risks in patient homes. For pediatric home care providers, these challenges are heightened by the distinct dynamics of providing care to children in their family environments. Pediatric caregivers balance clinical duties with behavioral management, family dynamics, and unique environmental hazards—often in homes that lack the structured safety of a hospital setting. Let's highlight some of these challenges and consider strategies tailored to the pediatric home care environment.

Recognizing Pediatric-Specific Risks in Home Care

Pediatric providers often work with children who have complex behavioral or medical needs, from developmental disorders to chronic conditions. Caring for these children requires not only clinical expertise but also significant skill in managing the intense emotions that can accompany pediatric care in the home. Parents and family members, deeply invested in their child's health and well-being, may be navigating an emotional roller coaster, dealing with the stress, fear, and frustration that come with their child's medical condition. This can create an environment charged with strong emotions, as family members may feel both protective and anxious, sometimes leading to heightened sensitivities or even conflict.

For providers, managing behavioral episodes safely requires an understanding of pediatric-specific responses and a readiness to adjust approaches to each child's unique needs. But equally important is the ability to communicate effectively with family members, some of whom may be struggling with feelings of helplessness, fear of the unknown, or even guilt. In such cases, providers may need to act not only as caregivers but also as informal counselors, offering reassurance while navigating heightened family dynamics. Sensitivity, empathy, and strong conflict resolution skills are essential tools for maintaining trust and diffusing any tensions that might arise.

Providers are also called upon to recognize and respect the family's routines, values, and emotional boundaries, while balancing their duty to prioritize safety. Training in de-escalation and family-centered communication strategies can empower caregivers to create a supportive partnership with families. This approach allows caregivers to address the family's concerns while reinforcing a safe, collaborative care environment that respects both the child's needs and the family's emotional journey.

Addressing Environmental Hazards: Firearms, Medications, and Other Risks

The presence of firearms in the home is a sensitive yet pressing issue in pediatric care. Providers can work with families to ensure firearms are stored securely and out of sight during visits, promoting a "no visible weapons" policy. Additionally, open discussions with families on safe firearm storage are essential for preventing accidental harm, especially in households with young or developmentally disabled children.

Common household hazards like accessible medications, cleaning supplies, and even pets pose additional risks in home settings. Pediatric providers are trained to remain vigilant to these risks and can work collaboratively with families to store dangerous items safely, particularly in spaces where curious young patients might roam.

Implementing Safety Protocols for Pediatric Home Visits

Comprehensive safety protocols are central to protecting providers and ensuring a secure care environment for pediatric patients. At the outset of care, thorough admission assessments serve as a foundation for understanding the home's unique characteristics and potential risks. During these assessments, providers can openly discuss safety concerns with the family, covering critical areas such as the presence of firearms, hazardous materials, and specific needs related to the child's condition. These proactive conversations also offer a space to discuss family dynamics and any concerns about the behavior of family members who may be under considerable stress. Addressing these issues early on allows providers to establish safety measures and set boundaries, reducing potential conflicts and fostering a cooperative environment.

Regular home safety assessments are invaluable for continually identifying and addressing hazards. In addition to evaluating items like medications and cleaning supplies, providers and families can work together to create "safe zones" within the home—designated areas where the child can be managed during behavioral episodes. Discussions around emergency exits, safe evacuation procedures, and clear routes can be critical if a family member's emotional response escalates into threatening or aggressive behavior. Setting these expectations can be a vital safeguard for both the child and the provider.

Many agencies are further strengthening safety protocols through training on pediatric behavioral safety, crisis management, and handling potentially hostile interactions with family members. This training equips caregivers with the skills to recognize early signs of aggression, respond to tense situations calmly, and de-escalate high-stress interactions. By preparing caregivers to manage challenging behaviors from both patients and family members, agencies contribute to a safer, more resilient care environment where providers can focus on their primary goal: delivering quality care to their pediatric patients.

Creating a Safety Partnership with Families

Building a safety-first partnership with families is essential to effective pediatric home care. Beyond initial safety assessments, caregivers can guide families in implementing ongoing precautions, such as safe firearm storage, securing hazardous items, and establishing calm environments conducive to care. By approaching these steps as a collaborative effort, caregivers reinforce a safety-conscious atmosphere that prioritizes the well-being of both the child and the provider. This mutual commitment fosters trust and ensures that safety remains a shared responsibility, ultimately enhancing the quality and stability of in-home care.

Supporting Caregiver Safety Through Policy and Resources

Home care agencies and policymakers play a critical role in fostering a safe environment for pediatric caregivers. Policies geared toward violence prevention, accessible agency support networks, and specialized behavioral health training for pediatric care are crucial measures that ensure provider safety in the field. These steps, combined with robust support from agencies, allow pediatric caregivers to concentrate on what they do best: providing safe, compassionate care to vulnerable patients.

The National Alliance for Care at Home has further enhanced safety in the industry through the development of a comprehensive resource hub designed to address emerging challenges and reinforce best practices. Developed over the past 18 months with contributions from leaders across the field, this platform offers a range of resources that can help agencies implement proactive safety protocols, guide staff training in behavioral health management, and strengthen agency response to workplace violence. By making these resources accessible, the Alliance provides valuable tools for agencies and caregivers alike, supporting them in managing risks and maintaining a safe, supportive work environment.

This focus on policy and accessible resources, including those available through the Alliance, not only improves safety standards but also empowers caregivers with the knowledge and tools needed to navigate complex in-home environments confidently. By fostering a collaborative culture of safety, we help ensure a resilient, prepared workforce capable of delivering high-quality, secure care to vulnerable pediatric patients in their homes.

Barriers to a Safe and Effective Discharge Home for a Neonate on Hospice Care

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Prenatal. Ms. Smith obtained regular obstetric care from her doctor in a country outside the United States. Three months before her baby was due, her doctors noted that the fetus had a complex cardiac anomaly. Not having the resources in her country to tackle such a complex problem, she was counselled to transfer her care, and the future care of her neonate, to a medical center in the United States that had expertise in pediatric cardiology.

Ms. Smith decided to come to the United States where she would wait until the baby was born, with the expectation that our health care system and expertise could cure him. Ms. Smith applied for, and received, state Medicaid. She sought prenatal care from a U.S. academic center's obstetrics department. Careful evaluation of the fetus here by Maternal Fetal Medicine, Pediatric Cardiology, and Pediatric Cardiothoracic Surgery revealed that the fetus likely had a complex cardiac malformation (hypoplastic right ventricle) which might not be surgically correctable, but might be able to be surgically palliated. Ms. Smith declined amniocentesis to check the genetic pattern of her fetus.

A prenatal consultation with the Neonatology group established that, at the time of birth, the baby would be shown to his mother, then transferred to the Neonatal Intensive Care Unit (NICU), for additional diagnostic studies, and medical management as appropriate.

First NICU Admission. At the time of his birth at full term, however, the baby was unexpectedly in full-blown respiratory failure. He was intubated and placed on mechanical ventilation, but remained in respiratory failure. While on the ventilator, he had episodes of severely low blood oxygen levels and of severely high carbon dioxide levels, accompanied by agitation and arching of his neck and back. A neurologic work up did not reveal any obvious problem with his brain, and his chromosomal result was normal. Endoscopy of his airway showed that his windpipe and bronchi had areas of severe narrowing, and, when he became agitated and tried hard to inhale, the airways collapsed completely, allowing no airflow at all. Moderate sedation made him not struggle so hard to breathe, thereby not collapsing his airways. Additionally, it was discovered that he was completely missing one lung and had no pulmonary artery going to that side. He "coded" several times due to his constellation of malformations, most notably, the airway collapse. The cardiothoracic surgeons declared that he was not a surgical candidate due to his combination of airway, lung, and cardiovascular malformations. He was followed by our academic center's pediatric palliative care team. As being intubated seemed to make him more agitated, he was extubated to nasal respiratory support, and kept sedated using pharmacologic and non-pharmacologic measures. At the mother's request, the baby's case was presented to other academic centers' cardiothoracic surgeons to see if they would operate on him. None of the other centers believed that they could correct his malformations or that he would have a favorable outcome. Ms. Smith was then amenable to taking her baby home, on nasal respiratory support, on a hospice pathway. We were able to find a community pediatrician who felt comfortable caring for this baby, with the help of the community hospice providers. A MOLST (Medical Orders for Life Sustaining Treatment) form was completed, stating that the baby was not to be intubated, or get chest compressions, when he eventually decompensated at home. Ms. Smith stated that she wanted to enjoy him at home for as much time as he might have, and anticipated that he would die at home, under the watchful support of the community hospice provider.

Discharge Home. The baby was discharged home on nasal respiratory support and on multiple meds to treat agitation. Additionally, he was not able to po feed due to his air hunger, so he was discharged home on nasogastric tube feedings using a feeding pump. Ms. Smith roomed in, in the Neonatal Intensive Care Unit, for several days and nights with her infant, with the goal of ensuring that she was skilled in providing his care, including being proficient in managing his nasal CPAP machine, oxygen delivery, medication administration, nasogastric tube, and feeding pump. A properly documented MOLST form was sent home with Ms. Smith.

At home. The mother noted that the baby, as in the NICU, had events of air hunger, arching, oxygen desaturations, and agitation. She became upset by these events, and called her community hospice provider for advice. The hospice provider gave her advice via telephone, but could not make an in-person visit. Ms. Smith went for 3-4 days without sleep due to the baby's agitation and air hunger, as well as the fact that the non-airconditioned apartment was extremely hot in the summertime. She did not bring the baby to his pediatrician due to the difficult logistics of getting transportation to the doctor's office. She brought the baby to the Emergency Department of the local hospital once via ambulance due to his air hunger. Once he had arrived there, however, his air hunger had largely abated, so the Emergency Department sent them back home. Ms. Smith called back to the NICU's pediatric palliative care team to try to get some respite, and it was then discovered that the community hospice providers had not received education in palliative care for the pediatric population. The hospice personnel did not feel comfortable providing hospice support for a neonate. Ms. Smith subsequently brought her baby to the emergency department of the academic center, not due to worsening of his condition, but due to the fact that she was not receiving the in-person support and respite that she needed. After just 5 days at home, the baby was re-admitted to the NICU.

Second admission to the NICU. As the baby grew, the significance of his airway narrowing slowly became less clinically significant. He was able to wean down slightly on his nasal respiratory support. He gradually transitioned from a hospice pathway to a palliative care pathway. The pediatric cardiology and cardiothoracic surgery teams at our institution adhered to their prior conviction that surgery would not be beneficial. The mother had frequent, daily questions for the cardiology and cardiothoracic surgery physicians, but they had already made their determination about the non-operability and hopelessness (from a surgical point of view) of his case. Consequently, they were not able to meet up with the mother to answer her questions on a daily basis, and had few interactions with the neonatology care team about his case, including recommendations about medications to try to control congestive heart failure. This relative deficit in interdisciplinary communication and communication between the subspecialist and the family created another barrier to creating an effective and reasonable discharge plan. It is possible that additional education of our subspecialist consultants regarding the fact that palliative care can offer concurrent care of medical problems might have served to re-engage these consultants to assist us in formulating a discharge plan that was safe and reasonable from a cardiac perspective. Because the baby had manifested slight improvement in his respiratory distress, the mother requested that we re-consult multiple pediatric cardiothoracic centers throughout the United States to see if, now, they would operate on him. During the time that these institutions were reviewing his case, the mother's visa expired, and she needed to go back to her home country for several weeks. Meanwhile, it became clear that no other centers believed that operative intervention would be beneficial.

Each time, as the mother prepared herself to take her baby home from the neonatal intensive care unit, she felt overwhelmed by the high-technology support he required. She stated that she had not felt empowered to take him home the first time, that she felt that she had not mastered competence in his care, and that she did not possess confidence in providing the complex care that he would require at home. It was not until the final week or two of his second NICU stay, with the help of our in-hospital pediatric palliative care team, that we developed a focused plan for the baby with a clearly-defined care-taking role for the mother. Lack of maternal medical expertise specific to their her baby's needs was another barrier encountered which prevented a safe discharge home. In retrospect, we recognize that our medical teams should provide better support for families and include them as care partners in these complex cases, particularly when the parents must rapidly gain medical expertise to function in the care of their baby when discharged out into the community. Preparation for discharge should begin at admission and must include all members of the multidisciplinary team.

After an additional 2-month stay in the NICU, the infant's air hunger improved slightly as his airway narrowing became less symptomatic. The community hospice providers obtained training in pediatric hospice care. The mother received intensive training in the medical and neurodevelopmental care of her baby, took advantage of rooming-in with her baby overnight and in the day, worked closely with the bedside nurses, and developed the skills and confidence that she needed to increase the chance of a safe and effective discharge home. Ms. Smith received some Medi-cab passes for traveling to future doctor appointments. She finally felt that she had the additional support that she needed to safely take her baby home again. So far, Ms. Smith has kept her baby at home in their apartment, and is enjoying his company.

In summary, major barriers to a safe and effective discharge home in the case of this baby included:

- lack of prenatal and postnatal advance care planning, due to the uncertainty as to whether surgeons in our institution or other institutions could correct the anatomic problem
- mother's temporary lack of availability for decision-making due to her visa expiration
- deficits in communication between the subspecialists and the mother, as well as between the subspecialists and the primary caretakers in the NICU
- a feeling of hopelessness and lack of subspecialist engagement in providing medical recommendations for a patient on a palliative care pathway
- time spent of the patient's limited lifespan in trying to determine whether other surgeons in other centers would operate on the him
- lack of education/experience of mother regarding provision of care to her infant at home so that she could feel both competent and confident in his care prior to discharge
- the mother's lack of transportation to get her baby to the pediatrician
- the initial lack of pediatric-trained personnel available in the community hospice, and lack of availability of respite for the mother

Safe and effective discharge of this baby to home with his mother required dozens of care providers, from bedside RNs, hospital nurse managers, respiratory therapists, pharmacists, advanced practice providers, and physicians from multiple disciplines within the hospital, as well as hospice physicians, nurses, and allied health professionals, a primary care pediatrician, social workers, case managers, physical therapists, medical equipment company providers, and more, to be working together seamlessly toward the one goal of getting the baby home safely to spend time with his family. Even though this patient was discussed multiple times in a complex care conference, we still were surprised by some of the details that we had overlooked.

Hospice Collaboration: When collaborating with a community hospice/palliative care team, it is important to get an understanding of their ability to take care of pediatric patients and how complex the patient can be. Since we have few hospices across the country that have pediatric specific teams, there are more teams that have adult providers that occasionally take care of pediatric patients, but do not have all the training that a pediatric team has.

Collaborating with a community hospice entails an in-depth review of the patient and what the needs will be going home. This may entail a discussion about transitioning to a hospice in-patient unit if the community hospice has access to one. This will provide the family with more time to learn the care needed for a complex patient, with the support of the hospice interdisciplinary team present to learn the care. Once the parent(s) are more comfortable with care, plans can be made to transition to the home setting.

In a case where a family is traveling from another country to receive care, the hospice team can also help navigate the community support needed for the family. This can be beneficial to the family in allowing them to connect with local supports that understand the needs of the family culturally, as well as providing them with the extra layer of support that may be available as they try to navigate not only being in a different country but learning medical care for a complex child as well. Advance planning regarding utilization of a translator phone/translator service for in-person visits, as well as for telephone communication, is essential when the family does not speak English well.

Providing the hospice team with an in-depth review of not only the medical needs of the patient, but the psychosocial needs, will prepare the team for the increased support that the family needs. The team then has an opportunity to prepare for the need for frequent home visits, and/or to prepare for telephone contact to make sure the family is adjusting to caring for a child at home. This also allows for collaboration with the hospital pediatric palliative care team so that each team can review what needs are being addressed and to determine which team will focus on which particular areas of need. For this case, the hospital team could have helped focus on transportation needs for any appointments, while the hospice team could have worked on getting Ms. Smith an air conditioning unit for the apartment as they were preparing to go home. If the hospital team started working on the visa application, the hospice team could have helped with the continued follow-up regarding the visa to make sure the required paperwork was updated in a timely manner.

Collaboration between the hospital teams and the community hospice can begin as soon as a patient with complex needs and a life-limiting illness is identified. Having all the teams working together as conversations with families begin, allows the hospital teams to know what the community hospice can and cannot provide in the home setting. Knowing the options early on, will help with adjusting home-going plans as the hospital course continues. Gathering more information on how the hospices in each area provide care to the pediatric populations is instrumental, allowing the health care providers in the hospital to know which hospice to reach out to when there is a need for pediatric hospice support.

Determining Medication Coverage for Children Receiving Concurrent Care Hospice in the Home

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For many parents the decision to choose hospice care for their child is overwhelming and gut-wrenching. Transitioning from a life-prolonging focus to "comfort measures only" can be an immense shift.

In 2010, the Patient Protection and Affordable Care Act (ACA) made this choice a little easier for parents. Section 2302, termed Concurrent Care for Children (CCC), allows children to receive curative-focused or life-prolonging care concurrently with hospice care. CCC eliminates the requirement to forego curative care upon election of hospice for children less than 21 years of age living with a six-month prognosis.[1] The CCC benefit ensures that parents are never forced to decide to stop life-prolonging therapies in order to receive quality care at home from an interdisciplinary hospice team focused on comfort.

Section 2302 states that a "voluntary election to have payment made for hospice care for a child (as defined by the State) shall not constitute a waiver of any rights of the child to be provided with, or to have payment made under this title for, services that are related to the care of the child's condition for which a diagnosis of terminal illness has been made".[2]

Pediatric Patient Case Example:

Bud has been undergoing chemotherapy for acute lymphocytic leukemia (ALL) and has not been able to achieve remission. His oncologist recommends admission to hospice for additional comfort support. His parents would like to continue curative-focused medications as well. Concurrent care allows Bud to continue receiving curative-focused therapies while enrolled in hospice care.

Prior to concurrent care, children and families commonly discontinued hospice care to seek more aggressive care in the acute care setting, used the emergency department service for acute symptom episodes, or delayed entry into hospice care as they hoped for a cure. Hospice care and subspecialty care were primarily separate. Once the intensive interventions being offered by the subspecialist could no longer achieve the child and family's goals, there was a break in service and payment structure to the subspecialist; hospice then would become the new provider. Concurrent

Care allows these two forms of care to be given simultaneously as part of a holistic care model. Patients younger than 21 years of age are entitled to receive the hospice benefit in addition to all necessary disease-directed therapies with the goal of providing access to comprehensive care to live as long and as well as possible.[3-6]

Concurrent Care plans of care are often complex and must factor in uncertain disease trajectories, complex chronic conditions requiring many subspecialists, difficulty delineating differences between comfort and life-prolonging entities of the care plan, and complications from medications and treatments.[6] Now layer on two different and distinctly unique care model payment approaches—hospice and subspecialty care. Hospice is paid a per diem to cover all the end-of-life needs of a child's terminal illness, while the subspecialist is paid through a managed care arrangement or fee-for-service to treat the child's illness.[7] Unfortunately, despite the federal mandate, most hospices are working with extremely limited guidance from state Medicaid offices and each state is handling the mandate differently.[8-9]

Bud continues to be seen in the oncology clinic regularly. His oncologist is still guiding therapy. Bud receives cyclophosphamide, palonsetron (Aloxi®), and many other medications per protocol in clinic. Per protocol, he also receives ondansetron (Zofran®) as needed for nausea/ vomiting and sulfamethoxazole/ trimethoprim (Sulfatrim®) for prophylaxis at home. Hospice has added on morphine (Roxanol®) as needed for pain and senna/docusate (Senna S®) as needed for constipation.

Per CMS guidance, Medicaid shall continue to be responsible to pay for disease-directed therapies in addition to the hospice benefit providing comfort-directed therapies. Medicaid shall reimburse appropriate Medicaid-enrolled providers directly through the usual and customary Medicaid billing procedures.[3,5] This transaction is complicated and outside the traditional Medicaid claims processing experience. Hospices should engage proactively with the state Medicaid office at the onset of hospice care to set communication expectations, train on concurrent care, and share care plans.[10]

Bud's oncology clinic will continue to bill Medicaid for the therapies received in clinic, including cyclophosphamide and palonsetron. Even though palonsetron is an anti-emetic, since it's administered in the clinic, it should be billed to Medicaid as it would have been prior to hospice election.

A hospice provider shall not be responsible for life-prolonging treatment, therapies needed as a result of a curative-focused treatment, medications prescribed by non-hospice providers/ subspecialists for the most part, or any aspect of the patient's medical care plan that is focused on treating, modifying, or curing a medical condition (even if that medical condition is also the hospice-qualifying diagnosis). Life-prolonging services and hospice services shall be billed/reimbursed separately despite being given simultaneously.[5]

Since Bud is receiving sulfamethoxazole/ trimethoprim for prophylaxis secondary to his chemotherapy regimen, this would be appropriate for concurrent care coverage. Sulfatrim® is being used for prophylaxis and is needed because of a curative-focused medication. This medication is directed by the oncology protocol. Sulfatrim® would be billed to Medicaid directly, outside of the hospice benefit.

Evaluating the indication guides medication coverage decisions. Hospice is still responsible to cover medications used to manage or palliate symptoms identified in the hospice plan of care, especially typical comfort medications. Hospice should typically cover analgesics, antiemetics, anxiolytics, and laxatives. Concurrent care medications, on the other hand, are more curative-focused, life-prolonging, prophylactic, disease-directed, maintenance therapy that the patient has been receiving prior to hospice medications.

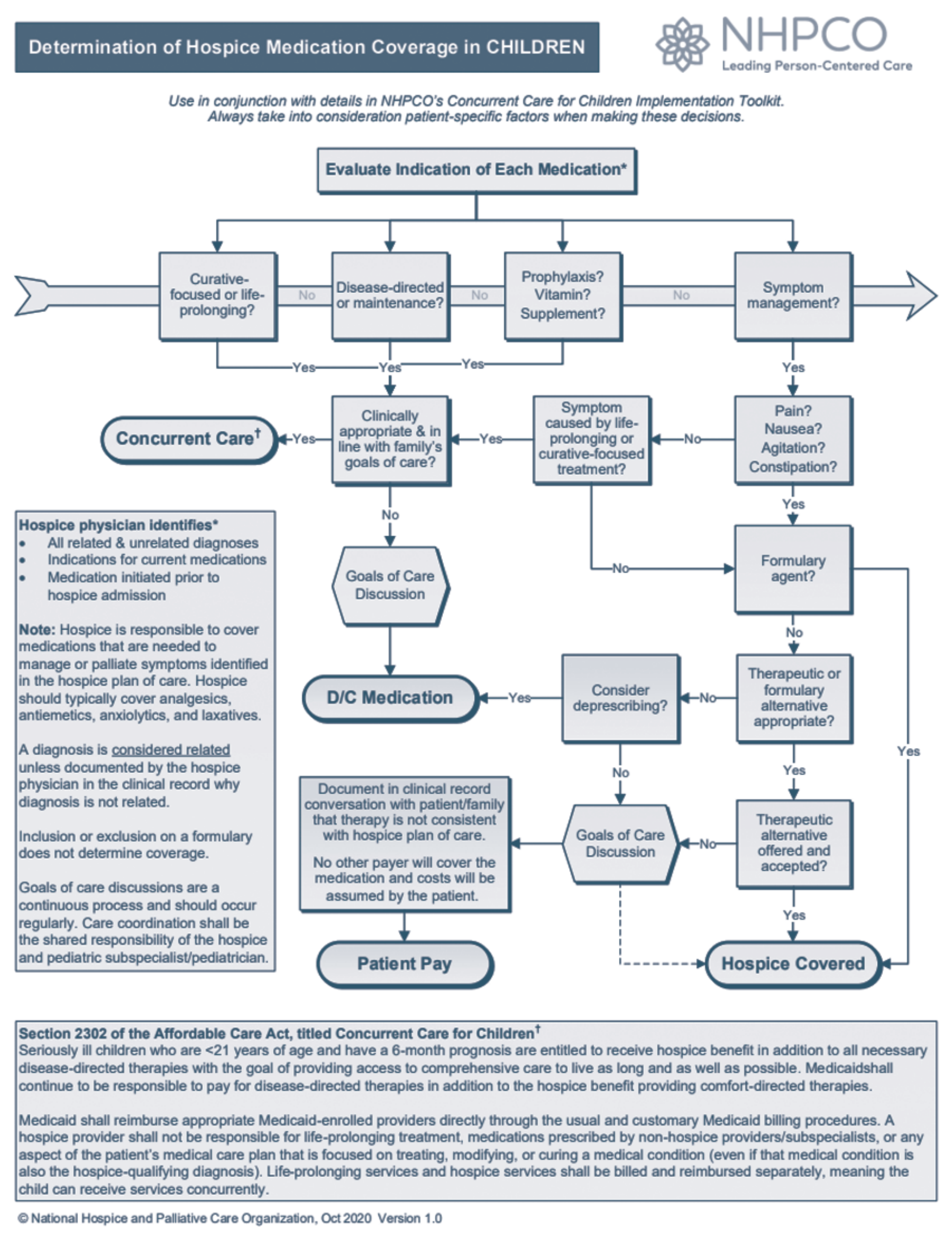
Despite Bud's ondansetron being started by the oncologist, the fact that it is being used for a common hospice symptom of nausea/vomiting means the hospice should probably cover it. Of course, the morphine and Senna S® should be covered by hospice as well since they were started by hospice for common hospice symptoms of pain and constipation.

Concurrent Care Covered Medications	Hospice Covered Medications
Life-prolonging	Comfort medications
Curative-focused	Analgesics
Disease-directed	Anti-emetics
Disease-maintenance	Laxatives
Prophylaxis	Anxiolytics

To standardize the medication coverage process for children receiving Concurrent Care, the National Hospice and Palliative Care Organization (NHPCO) Pediatric Advisory Council developed a medication coverage algorithm (Figure 1).[11] The first step in the medication coverage process is to evaluate the medication's indication. Most medications should fall into one of four main categories (listed at the top of the algorithm):

1. Curative-focused or life-prolonging
2. Disease-directed or maintenance therapy
3. Prophylaxis, Vitamins, or Supplements
4. Symptom management

Figure 1. Determination of Medication Coverage in Children[11]



Determination of Hospice Medication Coverage in CHILDREN

NHPCO
Leading Person-Centered Care

Use in conjunction with details in NHPCO's Concurrent Care for Children Implementation Toolkit.
Always take into consideration patient-specific factors when making these decisions.

Hospice physician identifies*

- All related & unrelated diagnoses
- Indications for current medications
- Medication initiated prior to hospice admission

Note: Hospice is responsible to cover medications that are needed to manage or palliate symptoms identified in the hospice plan of care. Hospice should typically cover analgesics, antiemetics, anxiolytics, and laxatives.

A diagnosis is <u>considered related</u> unless documented by the hospice physician in the clinical record why diagnosis is not related.

Inclusion or exclusion on a formulary does not determine coverage.

Goals of care discussions are a continuous process and should occur regularly. Care coordination shall be the shared responsibility of the hospice and pediatric subspecialist/pediatrician.

Section 2302 of the Affordable Care Act, titled Concurrent Care for Children†
Seriously ill children who are <21 years of age and have a 6-month prognosis are entitled to receive hospice benefit in addition to all necessary disease-directed therapies with the goal of providing access to comprehensive care to live as long and as well as possible. Medicaidshall continue to be responsible to pay for disease-directed therapies in addition to the hospice benefit providing comfort-directed therapies.

Medicaid shall reimburse appropriate Medicaid-enrolled providers directly through the usual and customary Medicaid billing procedures. A hospice provider shall not be responsible for life-prolonging treatment, medications prescribed by non-hospice providers/subspecialists, or any aspect of the patient's medical care plan that is focused on treating, modifying, or curing a medical condition (even if that medical condition is also the hospice-qualifying diagnosis). Life-prolonging services and hospice services shall be billed and reimbursed separately, meaning the child can receive services concurrently.

Most symptom management medications will be covered by hospice, especially if the symptom is a key hospice symptom of pain, nausea, agitation, or constipation. The exception is if the symptom was caused or exacerbated by a life-prolonging, curative-focused, or disease-directed therapy; then the medication would be covered under concurrent care.

Bud develops insomnia from one of his chemotherapy protocol medications. Anything used to manage his insomnia would then be appropriate for concurrent care coverage since the insomnia is being caused by his disease-directed therapy.

Tips for successful implementation of Concurrent Care:[9]

1. Establish the hospice contact within the Medicaid office.[10]
    - Contact your state hospice and palliative care organization or pediatric state coalition if difficulty determining the appropriate point person within the Medicaid office.
    - Work with other pediatric hospices in your state to determine a standard practice for implementation of Concurrent Care.
2. Provide training on pediatric Concurrent Care for families, subspecialists, and hospice team.
3. Develop and document the plan of care for concurrent care children with both the hospice and subspecialist.[12-13] Update this evolving plan of care regularly with documented sign-off from hospice, subspecialist, and Medicaid administrator.
4. Clearly define and document roles and responsibilities between the hospice staff and subspecialist including care coordination.[13]
5. Advocate for a Medicaid Concurrent Care Navigator to be assigned to the concurrent care children—preferably someone with clinical expertise such as a Registered Nurse (RN).[14-15] This position could bridge the gap between clinical practice and payment, while engaging with the hospice and subspecialists in care planning meetings and discussions to improve continuity of care.

In summary, Concurrent Care for Children allows children to receive curative-focused care concurrently with hospice care. While this is a federal mandate, implementation is state specific. Work with your state Medicaid office to implement Concurrent Care for your pediatric patients less than 21 years of age. Ensure appropriate documentation regarding coverage decisions. Therapies that are considered life-prolonging, curative-focused, disease-directed, maintenance, or prophylaxis are appropriate for concurrent care coverage. While the hospice will be responsible for managing typical hospice symptoms, such as pain, nausea/vomiting, agitation, and constipation.

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Massage Therapy Considerations for Home Care Delivery in Pediatric Palliative Populations

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As a palliatively-trained massage therapist, I offer symptom management and psychosocial support by way of skilled touch and therapeutic presence to children and young adults managing serious illness. Many of them face multiple hospitalizations and countless medical appointments every given year, which can cause an increase in stress and emotional hardship. Meeting these younger people where they are while in the comfort of their own homes helps to ease their burden.

Massage therapy for medically complex kids looks nothing like what robust and healthy adults receive from community providers. Researcher and educator Tracy Walton has written that “contact of some kind is almost always indicated, regardless of a person’s medical condition” so long as the clinician providing skilled touch thinks critically and has had appropriate training.[1] Massage therapists who have training in Oncology and Hospital-Based Massage Therapy know how to appropriately adapt elements such as site, pressure, positioning, pacing, and duration in effort to prioritize safety and comfort alongside the individualized needs of each patient.

Diagnosis, presentation of sign and symptoms, treatments, medical devices, patient’s energy level and communication abilities, interdisciplinary care team goals, and family goals and preferences are all considered when planning a palliatively-driven massage therapy home visit. My session for a nonverbal, non-ambulatory, 4-year-old child with chronic respiratory distress looks very different from the session offered to a verbal 20-year-old patient with thrombocytopenia post-bone marrow transplant. A younger child who experiences frequent seizures and dystonia may be offered a brief session of slow, gentle, predictable strokes compared to the moderate-pressure compressions and playful oscillating movement offered to an older child who is physically active and attends in-person school despite a history of cardiomyopathy. When common palliative care goals include comfort, mood enhancement, enjoyment, relaxation, and sensory stimulation, there is always some kind of support that I can offer. Beider, Maher, and Gold write that the significant reductions in anxiety alone resulting from massage therapy are encouraging outcomes for children with serious medical illness who may inevitably experience anxiety within their course of treatment.[2]

While massage therapy first and foremost involves touch, it is important to highlight the psychosocial components of care which do not involve hands-on contact. Kennedy and colleagues posit that massage therapy and its outcomes can be influenced by therapeutic relationships and communication, as well as by the therapist's education, skill level, and experience.[3] Many respondents in the study conducted by Keleman and colleagues valued the ability of the massage therapist to listen and to be in conversation with or to simply allow silence in support of the patient's experience. They write "the ability to understand and communicate (or not) sensitive health, lifestyle, and medical information, and to participate in care as an integrated member of a care team is an essential aspect to delivering this level of value."[4] Rodgers-Melnick and colleagues noted that while more than half of their recorded pediatric massage therapy encounters included no hands-on intervention, those participants also reported significant decrease in pain, stress, and anxiety after receiving psychosocial support and education from their massage therapist.[5] Parents benefit from the brief respite in caregiving as they squeeze in a quick snack, shower, or household task while I work with their children. Some choose to simply observe and later comment on their own increase in relaxation and calm. The care and support that I provide to families involves more than hands.

Flexibility, adaptability, and patience are critical, non-negotiable attributes for a massage therapist working with seriously-ill kids in the home. Keleman and colleagues observed that "effective massage delivery required massage treatment 'outside the norm –'that is to say, flexibility in timing and delivery given interruptions, noise, physical constraints, etc."[4] This has absolutely been my experience when working in families' homes, which are full of obstacles and distractions of which I have no control. I have conducted sessions in concert with sibling squabbles, video gaming tournaments, impolite pets, and well-meaning extended family members who express a lot of opinions about topics that have nothing to do with my service. I have paused to accommodate vest percussion therapy treatment, multiple diaper changes, medication administration, and suctioning support. It is not uncommon for a visit to end prematurely to allow space for a child's unexpected emotional outburst or lack of engagement. Fuhr and Drebhobl advise against continuing a massage through persistent crying, for it is unlikely to be of therapeutic value and may have a negative impact on future attempts at manual therapy.[6]

While I enjoy providing home-based support, this work is not without logistical challenges. Portable massage tables are out-of-the-question given their impracticality for small spaces, frequent sanitation needs, and potential for patient fall risk. They also put my comfort and preferences above that of my patients, which is the exact opposite of the goals that I am trying to accomplish. Trust, safety, and respect happens when I empower patients and their caregivers to choose the location for therapy. I have tucked myself into B's living room couch so that I can fully support his weight while he sweetly leans his body into my hands. I have worked while kneeling next to H's bed, who is dying from a glioblastoma, because that is the only place where she feels easeful and secure. C's massage happens while I lie on my belly on the floor, integrating touch during brief pauses in her play with piles of books, toys, and stuffed animals. The possibilities are endless when one lets go of expectations as to how a massage session is supposed to look.

Scheduling consistent patient visits that accommodate the requirements and preferences of multiple families living in the populous and heavily trafficked Bay Area is definitely one of the hardest parts of my job. The caregivers have an endless mountain of tasks related to their children's care: medical appointments with a multitude of providers and specialists, outpatient therapies with multiple agencies, in-home learning, school conferences, pharmacy visits, extracurricular activities, and all the phone calls and emails required to coordinate these things. Throw in an unexpected traffic jam on the San Francisco-Oakland Bay Bridge or a patient's need for immediate medical intervention into the mix and it's easy to see how last-minute cancellations and unaccomplished visits happen despite all of my best efforts to map my routes efficiently and reconfirm appointments while accounting for the scheduling needs of my families.

Parents express their gratitude frequently and often for their relief in not needing to take their children anywhere to receive my support. They freely and willingly share the challenges that they face when seeking outpatient care: G's mom fears that his car seat is causing blisters on his sensitive skin. R's parent tells me that R gets easily stressed out in traffic, which can escalate into hours of emotional outbursts and neurostorming.

Families hope for medical appointment times which minimize their travel burden so that they can better manage their children's discomfort while confined to their car seats and wheelchairs. These stories are what motivate me to get in my car and back out into traffic, serving families who may not have the resources necessary to access massage therapy providers in their local communities.

While massage therapy means many things to these families, it is never about fixing anything. It's about showing up and creating a safe space for positive touch experiences to happen. It's about offering a brief respite during their day, with emphasis on fun, comfort, pleasure, and relaxation. It's about meeting them where they are so everyone can just soften and take a deep breath, knowing that there is nowhere to go and nothing to be during our short time together. Most importantly, it's about enhancing the quality of life for kids who are more than their illnesses, who have their own unique stories to tell, no matter the extent of their medical challenges and how much time they have left to live.

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The Medicaid EPSDT Benefit: What Alliance Members Need To Know

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Background

In the Medicaid program, enrollees aged 21 and younger are entitled to the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit. EPSDT is intended to ensure that children have access to appropriate and necessary services, yet is a widely misunderstood component of the Medicaid statute. Additionally, due to the comprehensive requirements associated with EPSDT, many states that include limitations on services to children are out of compliance with Federal law. Increased awareness of the coverage mandates contained within EPSDT can help guarantee that children are able to access the supports and services they need to be healthy and to live safely in their own homes and communities.

EPSDT is defined in section 1905(r) of the Social Security Act and entitles children to a comprehensive set of services and supports. At the core of EPSDT is a routine schedule of well-child visits, also referred to as screenings, that states must establish. Further, EPSDT requires that states cover sufficient services, "to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services whether or not such services are covered under the State plan." In practice, this means that the "optional" and "mandatory" state plan services within Medicaid are actually mandatory for all children.

EPSDT Coverage Mandates

An important part of this discussion is outlining the "state plan" services that EPSDT encompasses. EPSDT's mandate specifically cites section 1905(a) of the Social Security Act, which lists a wide range of services and supports that can be covered by Medicaid. Optional services established under section 1905(a) include crucial supports such as Private Duty Nursing, Personal Care Services, Hospice, Dental, and Optometry, as well as many others. Because of their inclusion in 1905(a), EPSDT mandates that children have access to these services regardless of whether a state elects to cover them for adults. In contrast, other comprehensive home and community-based services, such as those authorized under the 1915 authorities in the Social Security Act, remain optional and are not included within EPSDT.

EPSDT mandates extend beyond simple requirements to cover services within the Medicaid program. States must also ensure that the services are sufficient to “correct or ameliorate” health-related issues that the children experience. CMS has adopted an expansive definition of “ameliorate,” including services that maintain a child’s current status and prevent any further deterioration. In other words, EPSDT interventions do not just apply to curative supports. CMS also mandates that sufficient amount, duration, and scope of services be covered based upon the needs of the individual rather than arbitrary limitations. CMS clarifies that, “services available to adults may include limits on the amount, duration, and scope of services that can never be exceeded (i.e., a ’hard limit’); states are not permitted to apply these kinds of limits to any service covered under EPSDT.”

Example

Some states may include a maximum number of weekly or monthly personal care hours covered by Medicaid. Such limits can only be applied to adults receiving personal care. Under the EPSDT benefit, the state must have a process to override this maximum and provide as many hours of service as are required based on the assessed need of a child.

Medical Necessity

Although EPSDT provides a comprehensive entitlement to care for children in Medicaid, states do have ability to mitigate overutilization by establishing medical necessity criteria that determines whether a service or support is appropriate for the child’s condition. It is important for providers and advocates to understand that state medical necessity criteria are not absolute; in fact, CMS stresses that, “medical necessity reviews cannot have the effect of imposing a hard limit for EPSDT-eligible children, nor can they result in inappropriate limits on access to a service.”

Under EPSDT, all medical necessity criteria must be established on an individual basis and cannot be applied in a uniform manner. Further, states must have a separate process to establish medical necessity for children that does not default the standard criteria and limits in place for adults.

Ensuring Access to Care

In addition to coverage, EPSDT also requires that states facilitate access to the actual services and supports. This includes ensuring there are a sufficient number of providers enrolled in Medicaid to deliver necessary services; assuring transportation is provided to children who need assistance attending appointments; and providing comprehensive information to children and their families regarding EPSDT and their ability to access services. EPSDT requirements apply regardless of whether the services are delivered via fee-for-service or managed care, and health plans must meet all of the same requirements regarding awareness and access if they enroll EPSDT-eligible children.

Information Requirements

CMS requires states to provide comprehensive information about EPSDT and the available services to families no later than 60 days after they are determined eligible for Medicaid. While useful, this information may not be fully understood by individuals and may also be overshadowed by the many other types of information provided and activities required when a family establishes Medicaid eligibility—for example, health plan selection. Providers can support their pediatric clients and families by having easy-to-understand information available about EPSDT and their rights to access care. This information should already be available from the state agency, so no new materials would need to be created.

Strategies to Ensure EPSDT Compliance

Despite the existence of comprehensive mandates under the EPSDT benefit, many states do not comply with the requirements. This may include "hard limits" on the amount of services provided to children, excessively stringent medical necessity criteria, and/or insufficient provider pool to meet the needs of eligible children. When an EPSDT deficiency is identified, care providers can support their members through several layers to help remedy the situation. For an individual, this includes:

- **Fair hearings and Appeals:** States are required to have a process for fair hearings and appeals that beneficiaries can use to dispute decisions regarding service denials, reductions, or excessive delays. There may be slightly different processes from state-to-state, as well as for individuals in managed care, but Federal law requires there to be adequate opportunities for individuals to appeal adverse decisions.
- **Complaint with Regional Offices:** CMS has 10 regional offices that are responsible for oversight of state Medicaid agencies. State-specific compliance issues can be reported to these agencies in order to initiate Federal oversight and corrective actions. Information about the regional offices is available here: https://www.cms.gov/about-cms/where-we-are/regional-offices
- **Lawsuits:** over the years, many lawsuits have focused on state noncompliance with the EPSDT mandate. Providers can support participants if they require legal remedy. Lawsuits can be filed by independent counsel or, for larger systemic noncompliance, beneficiaries can seek assistance from legal aid, protection, and advocacy organizations, and other beneficiary support entities.

Example

A recent lawsuit in New Mexico, upheld in the US Tenth Circuit Court of Appeals, found that the state Medicaid Agency was violating EPSDT by not ensuring access to private duty nursing services that were determined to be medically necessary. The state was ordered, "to take additional immediate and affirmative steps to arrange directly or through referral to appropriate agencies, organizations, or individuals, corrective treatment of in-home shift nursing services [...] at the level already approved by [the State], as required by the Medicaid Act,"

Resources for Further Reading:

CMS EPSDT Website: https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html

CMS EPSDT Manual: https://www.medicaid.gov/medicaid/benefits/downloads/epsdt-coverage-guide.pdf

EPSDT Best Practices Guidance: https://www.medicaid.gov/federal-policy-guidance/downloads/sho24005.pdf

US Department of Justice vs. Florida - Case No. 12-cv-60460-MIDDLEBROOKS/Hunt: https://www.justice.gov/d9/2024-01/order_of_injunction-u.s._v._florida.pdf

M.G., et al. v. Armijo, et al [New Mexico PDN lawsuit] – Case Number 23-2093 https://www.ca10.uscourts.gov/sites/ca10/files/opinions/010111113524.pdf

Readers' Corner

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Jarrell JA, Grossoehme DH, Friebert S, et. al. Challenges in Pediatric Home-Based Hospice and Palliative Care: A Case Series. ***J Pain Symptom Manage***. DOI: https://doi.org/10.1016/j.jpainsymman.2024.06.027

https://www.jpsmjournal.com/article/S0885-3924(24)00849-2/abstract

Summary

This is a pertinent, helpful summary of the challenges faced by pediatric patients, families, caregivers, and providers involved in the outpatient care of children with life-limiting conditions.

Who will benefit from this information? All involved in providing care in this setting will be helped by understanding the challenges and barriers to providing excellent care.

What are the main benefits and challenges to home-based care?

Benefits

- Improved patient and family quality of life.
- Decreased caregiver burden.
- Effective pain and symptom relief.
- Facilitation of peaceful death at end of life.
- Significant cost savings and decreased length of in-patient stay.

Challenges

- Lack of availability of home-based pediatric hospice in >70% of counties.
- Lack of pediatric home-based palliative care in >80% of counties.
- Inadequate access to hospice services in 30% of eligible children. Much of this access is through adult hospices.
- More than 50% of children's hospitals lack access to home hospice services.
- Lack of understanding pediatric hospice regulations
- Hospice organizational and administrative policies, poor reimbursement, and lack of staff trained in the care of children are likely causes of scarcity of services in rural areas.

Where and how can care be improved?

- Improve interdisciplinary education, training, and comfort in dealing with pediatric-specific issues such as managing pediatric pain and other symptoms, supporting siblings, addressing spiritual needs, and providing bereavement support for the family.
- Investigate the use of telehealth especially for discussions concerning goals of care and assessing the well-being of caregivers and family members.
- Help support understanding of current policies including hospice eligibility, that is challenging considering lack of predictability of the course of the illness or condition. Poor understanding, especially by primarily adult hospice providers, of Concurrent Care is frequently a barrier to the acceptance of a minor by the adult-focused hospice. Much education and staff support are needed in this area.
- Partnering of adult hospice with pediatric palliative care/hospice programs would address the concern of poor reimbursement of pediatric services.
- More research is needed to clarify knowledge gaps of adult providers caring for children and the use of telemedicine in the care of these children.
- Clinical care can be improved by ensuring that choice of medication, route of delivery, and use of equipment are appropriate to the child's age, stage of development, and size.
- Ensure that the child is involved in decision-making based on their maturity (not specifically age), willingness to contribute to the discussion, and knowledge of their condition and prognosis. Many such children are described as "wise beyond their years."
- Incorporate pediatric advance care planning where the child's assent is included in the shared decision-making between the patient, family/caregivers, and the providers. Frequently, the care plan changes over time as the clinical condition and/or goals change.
- Funding and financing remain challenging. Valuable team members including child life specialists, chaplains, bereavement specialists, case managers, and others are frequently not "reimbursed" for their important contributions.

Where to go from here

- Invest in more research including cost and benefits of telehealth.
- Develop strategies to partner pediatric palliative care with adult hospices.
- Improve education of and communication with adult hospice providers in the care of children and their families, and the inclusion of the child/adolescent in decision making.
- Continue to press for pediatric hospice reform and payment models that support interdisciplinary pediatric hospice/palliative care in the U.S.

Items of Interest!

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

As you'll see referenced throughout this publication, NHPCO has joined together with the National Association for Home Care & Hospice to form the National Alliance for Care at Home (the Alliance). The Alliance joins the two largest organizations representing, advocating for, educating, and connecting providers of care in the home for millions of patients and families who depend on that care.

The combined boards, leadership, and staff of NAHC and NHPCO engaged in a years-long, consultative process to form this historic alliance with the most powerful voice our community has seen fighting for our membership. Critically, the Alliance remains committed to pediatric palliative, hospice, and home care, and we continue our work in helping bridge the gaps with education, advocacy, and resources to help our community of pediatrics.

We have listened to our community and heard concern about "palliative care" no longer being included in the name of the new organization. This name was chosen for concision, and to reflect the full continuum of care patients living with an acute or serious illness can receive. However, the Alliance remains committed to all facets of palliative care, hospice, and home care. This workgroup remains committed to maintaining as many of our resources as possible as open access in support of this community.

On another note: The Items of Interest are only as valuable as the information shared. Please send us your news to share. E-mail to Christy.Torkildson@gcu.edu

Upcoming Conferences/Webinars:

- **Pediatric Palliative Care Webinar Series for 2025** has been announced. Calendar and more information, including how to register at https://www.ppcwebinars.org/
- **Courageous Parents Network.** There is an opportunity for our network of caregivers, clinicians, and others to come together to learn about topics relevant to the shared journey. On December 4th at 8:00pm ET, we will be hosting Dr. Wendy Lichtenthal, a clinical psychologist and grief expert. She will frame aspects of the grief experience across the caregiving trajectory and discuss using meaning and meaning making to help with coping. Go to the Courageous Parents Network website for more information.
- **ELNEC** has several upcoming courses; if you are faculty, you can get free access to the curriculum for your program/courses you teach.
- **AAHPM & HPNA Annual Assembly 2025** will be in Denver on February 5-8, 2025.

- **The Alliance Conferences Save the Dates:**
  - Chicago: July 27-29, 2025
  - New Orleans: Nov. 2-4, 2025

- **Have a conference to submit/share – send us the information to** Christy.Torkildson@gcu.edu.

Subjects and Contributors for Future Issues of this E-Journal

Our future issues will be centered on the following main themes. All issues are focused on a central theme providing perspectives from different disciplines and family members. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy at Christy.Torkildson@gcu.edu or Melissa Hunt at melissahunt3-1@gmail.com

Issue Topics: 2025

- **Issue #78:** Interdisciplinary Team, articles due December 15, distribution February, 2025
- **Issue #79:** Community as Bridge of Support
- **Issue #80:** Transitions
- **Issue #81:** The State of PPC: Policy Update, regional, state, national, global.

- **The Lucile Packard Foundation/Children's Health** publishes a monthly newsletter, "Children and Youth with Special Health Care Needs Network Newsletter. The newsletter includes state and national information that may be of interest. Subscribe to receive more information

NHPCO Pediatric Website Pages have been updated for easier searching!

NHPCO Palliative Care Online Resources:

- NHPCO has a variety of pediatric hospice and palliative care resources available at www.nhpco.org/pediatrics. **Two of our more recent resources include the updated Concurrent Care Toolkit and Working with Private Insurance Toolkit.** More palliative care resources are available at www.nhpco.org/pediatrics, including:
  - Community–Based Palliative Care
  - Legal and Regulatory Resources
  - Pediatric Concurrent Care
  - Resources for professionals and families
  - Webinars and Courses
  - Plus, more for NHPCO members

- **Did you know that the State Coalitions from Pennsylvania and California, with support from the Shiley Haynes Institute for Palliative Care**, host monthly, affordable webinars with continuing education units available? You can register for one or the entire series, with discounts for multiple registrations. Registration for the 2025 PPC Webinars opens on December 1! For more information, review the PPC website.
- **The Pediatric Palliative Care Coalition of Pennsylvania** has created a new resource the Self-Advocacy Toolkit: A Guide for Parents, Caregivers, Children and Adolescents.
- **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.

Pediatric Hospice and Palliative Care Resources:

- **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.
- **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.
- **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
- **NHPCO's Palliative Care Resource Serie**s 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.

- **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.
- **Questions about Concurrent Care?** Dr. Lisa Lindley and her team have created a wonderful website full of resources and information. You can access all the information for **Pediatric End-of-Life Care Research** at https://pedeolcare.utk.edu/
- **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.
- **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!
- **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.

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

National Alliance
for Care at Home

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