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WORKING TOGETHER AND INTERDISCIPLINARY TEAMS

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Issue Topic: Working Together and Interdisciplinary Teams

Welcome to the 78th issue of our Pediatric e-Journal. Our focus in this issue is on ways in which individuals and programs can work together in support of pediatric hospice and palliative care, with a special emphasis on interdisciplinary teams. Working together can take many forms, just as interdisciplinary teams can be composed of many elements. Because these are large topics, we recognize that no single issue will be capable of providing exhaustive coverage of these matters, but we hope that the articles offered here will spark broad discussion of this important subject area.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National 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 https://www.nhpco.org/palliativecare/pediatrics/

Comments about the activities of the Pediatric Advisory Council, its e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are open to suggestions for the three issues that will follow in 2025. Our tentative plans are for Issue #79 to address Community Bridge of Support and for Issue #80 to discuss care of adolescents and young adults. 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 melissa.hunt@handsofhopese.com

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

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Writing from Chile, this author argues for the value of “a partnership between the patient, family and the oncology team that considers conventional and integrative treatment, environmental factors, emotional/spiritual factors, and the role of other healing systems.” Further, he reminds us “that integrative medicine is a practice of evidence-based complementary medicine modalities within the conventional oncology setting, as an integral part of supportive and palliative care services being provided to patients.”

This article focuses “on the specifics of creating a dedicated pediatric hospice team through collaboration and communication with pediatric palliative care colleagues.” The authors ask: “If pediatric palliative care and hospice do similar things, why do children and their families need both?” Their answer is: “We believe the combination of these teams is essential to successful transitions of care across the entire continuum that is CCC [children’s concurrent care] hospice.” To be more specific, they focus on a family’s goals of care that can be shared between a community hospice team and a hospital’s palliative care program and they offer a scale to be “used in pediatric hospice and palliative care to aid in determining likelihood of a family/patient returning to the hospital to receive care in the setting of an acute event.”

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René Assetta Guilbeau, MSc, CCLS, & Bridget Perry, CCLS, MHA

An additional professional member of the hospice pediatric interdisciplinary team is the child life specialist (CCLS). According to these authors, "A CCLS is a degreed professional trained in providing psychosocial care and has the expertise and skills to help children, teens, and families process and understand their feelings and actions." Further, these authors argue that, "Providing developmentally appropriate information is important because children and teens understand death differently and the goal is to help them process and understand at their developmental level." They illustrate common reactions to grief at different developmental levels and suggest a number of "ways to help children and teens process their grief and learn how to cope."

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Oralea Marquardt, LCSW, Cassandra Prete, RN, BSN, CHPPN, Elizabeth Lung, MT-BC, & Kelly Outlaw, MS, CCLS

These authors argue that, “Through years of experience in community-based pediatric palliative and hospice care, our pediatric care team has found that joint visits where multiple disciplines collaborate in a single visit, offer a more comprehensive and integrated approach to care. Joint visits reduce the burden of constant appointments while also ensuring that the complex needs of the family are met.” They explain advantages of join visits involving nurses, social workers, music therapists, and child life specialists. This leads to their conclusion that, “The integration of joint visits into pediatric palliative care models should be considered a best practice, as it can significantly improve family satisfaction, reduce stress, and enhance the overall quality of care.” However, they also note that there are some circumstances in which joint visits may not be useful.

Home is Where the Heart is; Sharing in Care of a Loved One When Family Focus as the Interdisciplinary Team & Outpatient Palliative Care Offers Support with Pain & Symptom Management p. 32

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

The author of this article is a member of the workgroup that produces our Pediatric e-Journal. Here she describes the care that she and her family members provided to her sister before Jamie’s recent death. That care is described as the work of a type of informal interdisciplinary team. Obviously, this is not a pediatric situation, but the way in which this family came together to meet challenges and support a member at end of life is both praiseworthy and similar to the challenges faced by many families and the care they have offered when a child or adolescent is dying.

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Fallen Leaves

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I stood in my driveway on a crisp fall morning, facing my 50-year-old autumn blaze maple alongside an arborist. The tree was clearly ill, with pealing bark and branches devoid of their glorious red leaves. He gingerly broke our silence. “I’m sorry ma’am, I won’t be able to save your tree.” I replied factually, with a shrug. “All living things die eventually.” He turned to face me. “You’re a doctor, huh?”

I didn’t know I had a tell. My career as a pediatric palliative care physician has surrounded me with death, more than I care to acknowledge. I am witness to the whole life cycle, from birth to death, often all in one day. Perhaps hyperawareness of this fact, that each beginning has an end, has led to an overly pragmatic view of death.

Invariably, as I move deeper into my career, the shock and tragedy of it all has faded to reflection. Or maybe it’s those that surround me—an elderly neighbor texting about the maladies of old age, a friend mourning the loss of a parent—that have signaled this shift. My life has moved into a new Era, and therefore my thoughts also.

When my time comes, will I have control? To be at home, with my loves, and void of physical pain? Will those I leave mourn a life cut short or celebrate a life well lived? Will the replay of my life include all the beautiful moments I promised myself to remember forever and then forgot? Will the many children I’ve walked through this transition greet me on the other side with smiles or scorns?

What a joy this career is, to assist families in times of great need, to provide comfort when no one else can. It alters your person, as the arborist keenly noted. My patients’ have taught me the greatest of lessons; how to maintain perspective, to remain calm, and to savor the everyday. When the end comes, my end, I will find peace thru these teachings, a lasting legacy from those who lived many years too few.

How to Build a Bridge Between Conventional and Integrative Medicine to Improve the Quality of Life of Pediatric Patients in Palliative Care

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According to the World Health Organization (WHO), palliative care for the pediatric population comprises total active care of body, mind, and spirit, as well as providing family support, which should start when the disease is diagnosed and continue regardless of treatment for the disease.[1] This concept goes directly with the integrative meaning.

Improving quality of life is a basic premise and keeping patients pain-free is even more challenging. In countries like Latin America we have the habit of using pharmacological drugs to mitigate pain. We have improved technically, but we have forgotten humanized care, which is a non-pharmacological treatment. But why is it important to talk about non-pharmacological treatment for palliative care? It is crucial since approaching integrative medicine (IM) will allow us to deliver a safe, based on scientific evidence, high impact care, personalized for that family and its culture.

How can we define IM in palliative care? It's a partnership between the patient, family and the oncology team that considers conventional and integrative treatment, environmental factors, emotional/spiritual factors, and the role of other healing systems.[2] We have to remember that integrative medicine is a practice of evidence-based complementary medicine modalities within the conventional oncology setting, as an integral part of supportive and palliative care services being provided to patients.

Pediatric integrative medicine still has barriers like minimal access, few scientific studies, no health system insurance, ignorance of the meaning of integrative care, and lack of educational training in the area. The use of pediatric integrative medicine is estimated to be between 50% and 90% in Latin America. The prevalence of integrative medicine use in palliative care settings ranges from 29% in Canada, 43% in Germany, to 63% in Hong-Kong.[3]

Brazil is the country that has more publications about it, with a prevalence range from 4.5 to 50%.[4] In Chile in our experience, we have seen that 51% of our cancer pediatric patients use IM, also 50% of the patients do not tell the oncology team about using it, and 90% got the information from no regulated sources (internet or a friend).

The main symptoms that happen in palliative care are nausea and vomiting, pain, sleep and breathing disorders—all can be helped with an integrative approach.

In our experience, I remember a patient diagnosed with a brain tumor. After undergoing every possible treatment, he arrived with a poor quality of life, malnutrition, and a lot of pain medications. We began this journey with teamwork based on improving his nutrition, using supplements and an anti-inflammatory diet. For pain and muscle spasms, we began acupuncture treatment at home. He improved every day, even decreasing the pain killer drugs. We also used aromatherapy in conjunction with massages to reduce pain, muscle spasms, and improve his sleeping problems. At the end of the journey, the patient reached the end of life, but his quality of life and that of his parents improved considerably with teamwork and integrative medicine.

We can help our patients in so many ways. We need to encourage the patients and family to get closer to integrative medicine, under safety and based evidence therapies.

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Dr Roberto Campos Jeldres is a medical doctor with a specialty in pediatrics and subspecialty in hematology and pediatric oncology. APIM class scholarship 2022. He has created a bridge between conventional and integrative care in Chile's first Pediatric Integrative Oncology Unit, and is paving the way for a more holistic model of cancer treatment, centered on the concept of healing the "whole child" and enhancing the overall experience for patients and families.

The recent establishment of Chile's first Pediatric Integrative Oncology Unit marks a groundbreaking shift in the approach to childhood cancer care. This unit represents a comprehensive model that bridges conventional treatments with evidence-based integrative therapies, aiming to address both the physical and emotional needs of pediatric cancer patients. By integrating modalities such as nutrition, mind-body therapies, acupuncture, and physical activity, this unit seeks to enhance quality of life, manage side effects, and provide holistic support throughout the treatment journey.

Better Together: Creating Collaboration and Communication Between Pediatric Palliative Care and Hospice Teams

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The Patient Protection and Affordable Care Act[1] of 2010 included provisions for creating a Children's Concurrent Care (CCC) Hospice benefit. This allows children and families to access the support of an interdisciplinary team (IDT) of hospice professionals 24 hours per day while still pursuing life-prolonging care. There are not enough hospices with dedicated pediatric teams to meet the need. In recognition of this gap, some hospices will accept pediatric patients despite only having clinicians experienced in caring for the adult population. Losing a child is the worst thing any parent can imagine. Hospice affords parents the benefit of high-quality symptom management and shared decision making in the home, in addition to the option of end-of-life care at home. The hospice interdisciplinary team (IDT) is uniquely skilled to help both children and loved ones navigate this journey and provide bereavement support after death. This article will focus on the specifics of creating a dedicated pediatric hospice team through collaboration and communication with pediatric palliative care colleagues.

If pediatric palliative care and hospice do similar things, why do children and their families need both? We believe the combination of these teams is essential to successful transitions of care across the entire continuum that is CCC hospice. In contrast to the traditional model of the adult hospice benefit, CCC hospice allows children to continue subspecialty care, access the emergency department, and enable hospital admissions, all while remaining enrolled with hospice.

Most hospices do not share an EMR with their local hospitals. The palliative care team can help facilitate communication between the hospital, subspecialty services, and the hospice team. When a child is hospitalized and conditions change, palliative care has ongoing goals of care (GOC) discussions and can inform the hospice team of a family's evolving wishes. After discharge, hospice IDT members continue GOC conversations, and communication of those changes is essential. Children, especially newborns with complicated conditions, are often referred directly to hospice. These children commonly live longer than expected. Referring them to pediatric palliative care first can help families navigate which treatment options are in line with their values and goals for their child.

Hospice is able to provide many in-home services including intensive, in-home symptom management 24 hours per day, helping to keep children home when that is a family's desire. In many areas of the US, hospices are not able to utilize telehealth. Because pediatric hospice teams are often small and spread out across long distances, it can be very difficult to get to the patient in person. These barriers do not exist on the palliative side. Palliative care physicians and advanced practice providers are able to leverage telehealth to quickly respond to changes in conditions and continue to follow their pediatric patients, in conjunction with the hospice team. The IDT team including chaplains, bereavement coordinators, social workers, and child life specialists also provides in-home legacy making activities, counseling to parents dealing with anticipatory grief, specialized age-appropriate education, and support to families even after a child death.

Although communication between these two teams can be challenging, it is vitally important for the best care of children with serious illness. What follows are practical tips to establish and continue effective communication and collaboration. First, we suggest one main point of contact between each team. This is often a nurse manager on each side but can be anyone on the team who is able to receive and triage information to hospice and palliative team members involved. Although it is good to maintain an email/phone list of both teams that is updated regularly, having one point of contact ensures that no one who needs information about changes is left out of the loop. As staffing frequently changes, the main contact will always be up to date on who should get the appropriate information. Second, we have found that a quarterly joint lunch allows us to celebrate successes and troubleshoot service failures or lapses in communication. We also strategize on how to improve our collaboration and discuss new ideas about symptom management, as well as limitations on both sides to create reasonable expectations for patients and families.

In addition to the systems outlined above, creating a formulary of specific medications and list of equipment that hospice routinely provides helps palliative care understand what hospice can cover and what needs to be obtained elsewhere. Most adult hospice nurses are inexperienced with weight-based dosing, varying concentrations, and making on the spot calculations of doses. Having a formulary with all doses based on weight helps physicians and advanced practice providers respond quickly and safely to a need. Collaboration in advance has assured that the hospice pharmacy has these medications and concentrations available and are covered by the hospice benefit. Nurses and pharmacists can double check the dosing using the weight-based formulary.

Both teams and the pharmacy can approve the formulary in advance so there is consensus when children are getting care from multiple providers. This can be reviewed and updated every six months or more frequently as needed. The NHPCO Determination of Hospice Medication Coverage in Children is an excellent tool to reference in creating this type of formulary, to help understand what is covered under hospice and what falls under CCC.[2]

Finally, these authors struggled in the beginning months of collaboration to understand where families were along the continuum of decision making. This was particularly challenging when a family called after hours, or their regular hospice nurse was unavailable. Giving appropriate advice to families was difficult when their current GOC were not well understood. GOC ranged from never returning to the hospital seeking exclusively comfort care at home, to always wanting care in the hospital. In light of the fact that goals often change as illness progresses, it was paramount to understand a family's current status in order to give goal-concordant advice.

After struggling for several months to communicate changes, our teams created a scale to summarize a family's current GOC. Through a Plan, Do, Study, Act quality improvement approach, we formulated and revised a scale until we found a version that enabled effective and efficient assessment of GOC, easily accessible to both teams. The PAR Scale (Preferences for Acute Rehospitalization) can be seen below. Of course, this is a summary of very nuanced and complex conversations and should be taken in the context of each unique child and their situation. Nevertheless, it serves as a starting point for urgent responses. In a survey of providers using the scale, a large majority agreed that it was helpful to understand a family's current goals for their child and give goal-concordant advice to families.[3] (accepted for publication in the *Journal of Palliative Medicine*). The scale is initially reported when a family is referred to CCC hospice, and confirmed by the hospice at the time of admission. It is used as a starting point for conversation by various team members, and the current scale is communicated at set times (hospitalization and after each IDT), along with after any changes sparked by new conversations.

A 2020 study showed that 40% of children's hospitals in the US still lack access to hospice care for their pediatric patients.[4] To expand access it is likely that primarily adult teams will continue to care for children in hospice care. Communication and collaboration between palliative care and hospice teams is essential to providing good care for children who access ongoing life-prolonging care while in hospice. We believe that by putting some or all of the above processes into place, children can receive safer and better goal-concordant care while utilizing the CCC hospice benefit. This is particularly important when care is provided in part or wholly by primarily adult hospice team members.

PAR Scale: Preference for Acute Rehospitalization

1. **Family never wants to return to the hospital**
   - **a.** Care exclusively focused on comfort, not interested in life-prolonging treatments
   - **b.** Treat potentially reversible things at home
2. **Family never wants to return to the hospital, except for end-of-life care**
   - **a.** Care exclusively focused on comfort, not interested in life-prolonging treatments
   - **b.** Treat potentially reversible things at home
3. **Family would consider staying home if patient remains comfortable, even if time were shorter**
4. **Family is leaning towards returning to the hospital, will call hospice to consult first**
5. **Family always wants to return to the hospital**

Figure 1: Pediatric PAR Scale

PAR Scale developed by Kelley Newcomer, MD and Katherine Maddox, MD, University of Texas Southwestern Medical Center and VNA Hospice of Texas. PAR Scale is used in pediatric hospice and palliative care to aid in determining likelihood of a family/patient returning to the hospital to receive care in the setting of an acute event.

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Interdisciplinary Onboarding

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Interdisciplinary collaboration has become a cornerstone of effective healthcare delivery, particularly in hospice and home health. These settings, which provide critical care to individuals with chronic illnesses, terminal conditions, or significant functional impairments, require a nuanced approach that addresses the multifaceted needs of patients and their families. The complexity of care in these environments calls for integrating diverse expertise and perspectives, a hallmark of interdisciplinary collaboration.

In hospice and home health care, the patient's journey is often marked by medical, emotional, social, and spiritual challenges that cannot be addressed in isolation. Physicians, nurses, social workers, chaplains, and aides bring distinct knowledge and skills to the care team, creating a holistic approach that enhances outcomes and ensures the individual's dignity. This collaborative framework improves clinical effectiveness and fosters communication and trust among providers, patients, and families (Geese & Schmitt, 2023). This interdisciplinary approach is even more necessary in the pediatric environment. Pediatric hospice professionals balance understanding the unique developmental stages of children, communicating effectively with families facing complex situations, managing pediatric-specific symptoms, navigating the emotional aspects of caring for dying children, and being aware of the psychosocial and spiritual needs of both the child and family unit, all while considering the family's cultural and religious beliefs and practices.

Despite the well-documented benefits, barriers such as fragmented communication, role ambiguity, and systemic challenges often hinder optimal interdisciplinary collaboration (Zajac et al., 2021). Addressing these obstacles is imperative to achieving the seamless care coordination essential in hospice and home health settings.

By understanding and embracing the principles of teamwork and shared decision-making, healthcare professionals can create an environment where every patient receives compassionate, comprehensive, and personalized care. A large part of this requires an understanding of what each team member does, or is capable of doing, in their respective role. This article will discuss how one hospice organization enhanced interdisciplinary team dynamics through their onboarding process.

When I began my career as a hospice nurse, my administrator and director emphasized the importance of understanding the full scope of hospice care. Before I joined the nursing staff, I spent an entire week learning what other hospice professionals did for our patients and their families. I accompanied the chaplain and social worker on visits, observing how they worked independently and together to meet both patient and family needs. I spent time with the bereavement coordinator, gaining insight into the services provided to families before and after a patient's passing.

During training with the volunteer coordinator, I was amazed by the many ways volunteers supported patients and families. I also spent a day traveling with a home health aide, where I witnessed the deep personal connections they formed with patients and their families. Finally, I spent time in the office, shadowing the admissions coordinator to learn about the intake process and observing the crucial work handled by the administrative team. Even today, I remain impressed by the scope and complexity of their contributions.

This experience gave me a profound appreciation for how multi-faceted the hospice team truly is. As a nurse case manager, I realized I didn't need to manage everything on my own. I learned when to involve the chaplain, refer families to the bereavement coordinator, or tap into the expertise of the volunteer coordinator. I recognized when it was beneficial to do dual visits with the social worker. For example, I remember a few patients who I could tell were not being truthful when I assessed their pain. My social worker would visit the family with me. She would talk with the parents while I assessed the patient. Since there was no longer a parent in the room, my patients would feel more comfortable telling me how they really felt. Each time it happened, upon debrief, I would tell the social worker that the patient was hiding their pain because they don't want their parents to be sad. She would tell me that the parents told her that they thought the patient was "putting on a brave face." Understanding the roles and strengths of each team member allowed me to focus on what I did best, knowing that my colleagues were equally dedicated to delivering the best possible care.

Sometime later, I transitioned into the role of Director of Professional Services. One of my first major initiatives was to overhaul the onboarding process. The documentation was outdated, the steps varied across disciplines, and, most importantly, I believed everyone deserved the same interprofessional experience that had profoundly shaped my understanding of hospice care. My goal was to ensure that new hires not only learned about their own roles but also gained a comprehensive appreciation for the contributions of their colleagues.

When the revised onboarding process was presented to the current staff, it sparked mixed emotions. While many were excited about the changes, others expressed frustration that they had never been given the opportunity to learn from the different disciplines in the same way. This feedback motivated me to arrange for them to have a version of this experience. As a result, several staff members chose to proactively engage in the interprofessional experience. Over the next three months, 12 nurses, 15 home health aides, 2 social workers, 1 chaplain, and 1 admissions coordinator chose to accompany their colleagues on visits to observe and better understand their roles.

The impact of these changes was immediately evident during our weekly Interdisciplinary Team meetings. Discussions about patients and families became more collaborative and solution focused. Instead of nurses expressing uncertainty about how to handle specific challenges, they were actively involving other team members. Nurses were reporting how they had reached out to the chaplain for spiritual support, consulted with the volunteer coordinator for additional resources, or involved the bereavement coordinator when family dynamics required extra attention. The enhanced collaboration not only improved patient care but also fostered a stronger sense of teamwork and mutual respect among staff.

When I reflect on my journey in hospice care, the importance of interdisciplinary collaboration stands out as the cornerstone of delivering compassionate, comprehensive, and personalized care. From my early days as a hospice nurse to my role as Director of Professional Services, I've witnessed how understanding and leveraging the diverse expertise of a team transforms patient care and creates a supportive work environment for staff. From a personal standpoint, it showed me that I didn't need to carry every burden alone. I knew exactly when and how to involve others, which made me a more effective nurse and allowed patients and families to receive more tailored support. Later, when the opportunity was offered to others, it spurred a flurry of voluntary interprofessional shadowing. Staff wanted to gain new insights into their roles and responsibilities.

This journey reinforced for me the power of interdisciplinary collaboration in hospice care. By fostering an environment of teamwork, shared decision-making, and mutual respect, we created a culture where every professional felt empowered to contribute their expertise, and every patient and family received the comprehensive care they deserved. I'm proud of the work we accomplished, and I hope this approach inspires other organizations to prioritize and invest in interprofessional collaboration.

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Social Work in Pediatric Hospice Care

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Pediatric hospice is a field that involves compassion, expertise, and an understanding of the complex emotional and medical challenges faced by children and their families. A pediatric hospice social worker plays an important role on the interdisciplinary team, offering emotional support and collaboration with every discipline to ensure a holistic, individualized plan of care.

The Role of a Pediatric Hospice Social Worker

Serving as a hospice social worker for the last decade, my job is to meet a child and family where they are in their medical-emotional journey, walking beside them during the child's end-of-life processes. Every case is unique, requiring skilled, individualized assessment with multiple interventions aimed at honoring the diverse cultural, religious, and spiritual backgrounds of each family, as well as becoming familiar with their internal family culture and priorities.

Let's take a deeper dive into some of the different aspects of hospice social work:

1. **Therapeutic Interventions:** Social workers learn multiple therapeutic interventions while in school and throughout their career. It is important for the social worker to match the appropriate therapeutic intervention to meet the needs of families. Some of the more common interventions used include assisting families with reducing anxiety related to end of life, exploring feelings related to end of life, active listening, and crisis intervention.
2. **Emotional Support:** Social workers help children and families cope with the emotional impacts of terminal illness. When I think of the emotional support provided by social workers the video on empathy from Brene Brown often comes to mind. Brene Brown teaches that empathy requires being comfortable sitting in a "dark hole" with the individuals to make a connection that creates a space for them to openly share their fears and worries, as many people in their lives are trying to pull them out of the "hole." Often, simple presence and acknowledgement of the crushing weight of terminal illness on children and parents can most honor their sensitive experience.
3. **Facilitating Difficult Conversations:** Social workers can help facilitate conversations between the family and the medical team. This includes helping to understand a medical diagnosis, prognosis, and treatment options. I often work with families who are unsure about medical interventions presented by their specialist providers. The nurse and social work team can help

assess goals of care and questions for families to further discuss with their medical provider that are in alignment with their family priorities. The goal always is to ensure they are making the best and most informed decision they can in these very difficult moment in their child's life.

4. **Advocacy:** Social workers advocate for the needs of the families, ensuring the care plan reflects their needs, cultural beliefs, and goals. Social workers assess all of the community programs involved and advocate for families who require assistance collaborating with or accessing these programs. For example, the nurse and I have attended school IEPs to make sure the IEP goals determined by the school align with the child/family's goals. If extensive support is required, social workers can refer families to organizations that specialize in advocating for children with complex medical needs within the school system.
5. **Education:** Social workers may offer educational resources about the dying process, how to prepare for the child's death, and what to expect during the final stages of life. For families whose child on hospice has siblings, I have often provided education on common responses to death for children of different ages and developmental levels. Much of the education offered by the hospice team is reiterated throughout their journey as the education can be challenging to absorb during such a mentally and emotionally taxing time.
6. **Resources:** Social worker are constantly assessing for family needs and connecting to resources. These may be needs for basic survival, such as financial support to help with bills, rent, care payments, groceries, and gas. Often times families require these needs to be met in order to focus on resources that are geared more toward memory making, such as the fun of a wish trip, a camp, or adaptive activities. We are fortunate to work with several organizations who are like-minded and have a focus on improving quality of life for families. Many of these organizations were created by families who experienced the death of a child.
7. **Supporting Siblings:** Siblings of children diagnosed with a terminal illness often may not receive the same amount of attention as the child who is terminally ill. Parents may feel guilt for not having as much "time" as they once had for their other offspring. The social worker can validate the parent's emotions, then work with parents on ways to make siblings feel included and special. The social worker may visit siblings for therapeutic interventions if desired by the parent. Social workers look for programs offering support or fun activities for siblings. This could include programs catered to the sibling's own interests, including sporting events, art activities, or any other communally accessible program focusing on the sibling's personal enjoyment.

Social Work in an Interdisciplinary Team

The pediatric hospice interdisciplinary team brings together multiple healthcare professionals in collaboration with the family who are the true experts on their child's care. This typically includes social workers, physicians, nurses, spiritual care advisors, home health aides, and grief support services, and may include integrative therapies such as art, massage, or music, or other specialties like Child Life, Physical Therapy, or Occupational Therapy.

I am a firm believer that a strong collaborative relationship between nursing and social work offers the highest level of care to families. Joint visits can be beneficial to allow more comprehensive and efficient visits for families who are often busy and overwhelmed. Joint visits also create an opportunity to provide consistent care. For example, if the nurse is talking with a patient about anxiety keeping them awake at night, the nurse can focus on the medical piece and the social worker can offer a different perspective, discussing options like breathing techniques or meditation.

Collaborating with physicians includes educating myself on a child's diagnosis so I can provide appropriate education and support. In my role, I can ensure the physician understands a family's cultural or religious needs that could impact their decision-making process as the child's illness progresses.

Spiritual care is an essential part of pediatric hospice care for many families. A common misconception is that spiritual care only offers religious support. Spiritual care advisors help children and their families navigate not only religious but also spiritual and existential concerns. Like social work, spiritual care advisors provide a great deal of active listening and emotional support. Social workers are often communicating with spiritual care to discuss ideas on how to best support a family.

Child Life Specialists can deeply enrich a pediatric hospice team through different facets of their specialty training. They may provide ongoing grief support, collaborate with families on legacy building activities, or help patients and siblings learn and cope through play therapy. Collaboration between social work and the child life specialist can ensure comprehensive anticipatory grief and bereavement care that prioritizes the developmental needs of children and their caregivers.

Participating in an interdisciplinary pediatric hospice team can carry a heavy emotional toll. One way I have coped is by leaning on the team I work with. When leaving an emotional visit, the nurse and I often make a phone call to process the visit. The manager of our program also worked in the field and has a deep understanding of the challenges the team faces. She always offers an open door and additional support if/when a member of the team requires. The physician and spiritual care teams offer perspectives different than mine that can help see difficult situations in a new light. Over the past 10 years I have found that being a pediatric hospice social worker has been rewarding and humbling. On the difficult days, I try to focus on the difference our program has made for families during the most difficult time imaginable. It is incredible to witness how many lives are inspired (mine included) by the children I have worked with throughout my hospice career. A thriving interdisciplinary team that respects and prioritizes social work supports not just patients and families, but also each other, by acknowledging and learning from the unique strengths of each discipline.

Strengthening Pediatric Palliative Care with Psychologist Integration

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The inclusion of psychologists in pediatric palliative care (PPC) is growing, in part due to increasing clarity about their unique role and broad skillset as scientist-practitioners. Psychologists' expertise both complements and adds to the often-robust services families already receive as part of PPC (Edlynn & Kaur, 2016; Thompson et al., 2024). This article defines PPC psychology as a new and growing field, summarizes the role of the psychologist as part of PPC, and further illustrates their skillset with a patient case example.

Defining PPC Psychology

Compared to clinical child psychology, pediatric psychology refers more specifically to the field of health psychology for children, adolescents, and young adults. Pediatric psychologists receive specialized training in acute and chronic illness, psychological assessment and intervention using the biopsychosocial model (Engel, 1977), consultation and liaison skills for healthcare settings, multidisciplinary research, and interventions for medical referrals, such as medication adherence and pain management (Palermo et al., 2014; Spirito, 2003). Although recent survey data suggest that most pediatric psychologists are not fully embedded as "core" members of PPC teams (Hildenbrand et al., 2021), they often work in specialties that are "frequent flyers" for palliative care (e.g., Oncology, Pain, Solid Organ Transplant). Psychologists' roles are "vast and varied" (Thompson & Kentor, 2021, p. 226) and their services are delivered in close collaboration with other members of the PPC team, with the understanding that aspects of these roles overlap.

Psychologists' increasing involvement in PPC led to the development of formal competencies and professional standards for PPC psychology (Thompson et al., 2023). The competencies span six domains (Science, Application, Education, Interpersonal, Professionalism, and Systems). Although a detailed description is beyond the scope of this article, it is clear that PPC psychologists' skills transcend that of skilled assessment, intervention, and consultation. Indeed, they contribute to research and the development of new palliative care interventions, training of medical and mental health trainees, patient advocacy, quality improvement, and program development efforts.

Psychologists as Part of the PPC Team

There is a need to integrate psychologists into PPC more systematically (Thompson & Kentor, 2021; Thompson et al., 2024). Psychologists value the unique expertise of other PPC specialists and collaborate with them to achieve shared goals of care. Psychologists may partner especially closely with child life specialists and others whose role emphasizes supporting a child's coping and adjustment to illness. As a consultant, psychologists share assessment findings and provide recommendations to address any symptoms that are interfering with medical care and/or access to other necessary services. Psychologists can see patients together with the team or separately. Many psychologists offer therapy services via Telehealth, which is helpful when patients are home and/or too sick to travel. Fully "embedded" PPC psychologists may need to work with other pediatric psychologists to determine who is taking the lead when patients are followed by multiple teams (e.g., oncology and the PPC team). Depending on the model of care, it may not be necessary for psychologists to see all patients; these decisions are made through careful assessment, family input, and team consultation.

Intervention Delivery

Pediatric patients with life-limiting conditions report poor quality-of-life when PPC services are initiated (Lee at al., 2022) and individuals with medical conditions experience higher levels of mental health symptoms in general (e.g., Abramson, 2022). PPC psychologists treat impairing physical and psychological symptoms using interventions that are supported by research (Hildenbrand et al., 2021; Thompson et al., 2024). They use a strengths-based, family-centered, trauma-informed approach and distinguish pathological symptoms from the expected (and usually adaptive) reactions to critical illness and grief. Furthermore, PPC psychologists are experts in child development and knowledgeable about how patients understand illness and death across the lifespan, which is imperative in navigating highly sensitive conversations and guiding families in medical decision-making. Consistent with the overarching mission to provide culturally sensitive palliative care (Wiener et al., 2022), psychologists assess and uphold families' unique backgrounds, values, beliefs, and preferences. In general, they are flexible and creative to ensure psychological interventions are accessible to patients whose illness may affect participation. See Table 1 for information about the types of interventions delivered by psychologists in PPC.

Table 1. Psychological Interventions in PPC

Area of Focus	Description
Emotional Support	Like many clinicians in PPC, psychologists use "micro therapeutic skills" (e.g., reflection, active listening) to maintain rapport and establish a psychologically safe therapeutic space. As they guide families in expressing and processing emotions, they incorporate normalization, psychoeducation, and anticipatory guidance. They work diligently to establish trust and destigmatize mental health services.
Interventions for Emotional and Behavioral Symptoms	Psychologists deliver evidence-based interventions to address internalizing symptoms (e.g., anxiety, depression) and externalizing behaviors that cause distress and may interfere with medical treatment. Examples include cognitive-behavioral therapy, motivational interviewing, dialectical behavior therapy, acceptance and commitment therapy, parent management training, trauma-focused cognitive-behavior therapy, and meaning-centered therapy (Kearney & Ford, 2017).
Interventions for Physical Symptoms and Adherence	Psychologists are knowledgeable about the mind-body connection and biopsychosocial factors that affect functioning. To help patients with acute and chronic illness, they use non-pharmacological interventions to manage pain and other physical symptoms, behavioral sleep intervention, strategies to improve medication adherence, pill swallowing training, and interventions to reduce procedural distress and/or medical phobias.
Communication Interventions	Psychologists assess communication preferences and goals, reinforce effective communication strategies, and support families and teams in having difficult conversations. They address "mutual pretense" (Bluebond-Langner, 1978) by promoting open communication and recognize that disclosing information often has tremendous benefits (e.g., reduces anxiety). They help families communicate during times of crisis and grief, and work with teams and families to resolve conflicts and approach ethical dilemmas.
Advance Care Planning and Decision-Making	Families and patients in PPC spaces confront difficult decisions. Psychologists reinforce patients' and families' autonomy and support values exploration to help guide decision-making. They use established tools, such as *Voicing My Choices* (Wiener et al., 2021) or *My Wishes*, for advance care planning.
Other Interventions	Psychologists recognize the critical importance of self-care and are often involved in leading bereavement rounds or similar wellness initiatives. They advocate for the involvement of other specialty services and provide bereavement services.

Patient Case Example

A case example (representative of a common psychology treatment plan in PPC) is provided here to further illustrate the above information. Many details were changed, and aspects of multiple patient scenarios were combined to ensure anonymity. It is important to note that many team members played a critical part in this patient's care, and interdisciplinary consultation was essential. "Marie" (pseudonym) was a 9-year-old with refractory, progressive cancer. Supported by her loving parents, she loved sports and playing video games.

Marie was cared for by her oncologist, child life specialist, social worker, and multidisciplinary palliative care team. Marie reported feeling mostly angry and sad, in contrast to her typical upbeat nature. I met with Marie both in person and virtually via Telehealth, and she enjoyed talking from the comfort of her home. Our treatment plan included individual, family, and parent guidance sessions. Earlier sessions were spent building rapport with Marie and her family, normalizing her emotions in the context of her cancer experiences, and supporting them in understanding the interaction between her physical and mental health. Through my initial assessment, clinical interview, and cultural formulation, I conceptualized Marie's symptoms and identified an appropriate mental health diagnosis that considered her significant medical stressors and symptoms. Marie's changes in functioning (e.g., reduced appetite, fatigue) alarmed her family; therefore, significant interdisciplinary teamwork was essential to problem-solve and address these concerns. Marie sometimes communicated her distress by making statements that raised concerns about her safety. I applied my skills in child development and risk assessment to interpret their meaning and acuity, and communicated my findings, which were reassuring, to Marie's parents and care team.

In addition to validating and normalizing her understandable emotions, we identified cognitive-behavioral strategies to improve her mood and reduce anxiety, which included ideas for distraction, behavioral activation, and challenging "thinking mistakes." With Marie's permission, we shared these tools with her parents and relevant members of her team to reinforce their application. As her disease worsened and she experienced more pain, we focused intentionally on non-pharmacological pain management. Marie learned about the "gate control theory" (Melzack & Wall, 1965) in child-friendly terms, and practiced "closing her pain gate" through diaphragmatic breathing, progressive muscle relaxation, distraction, and integrative health services (e.g., acupuncture, massage). Marie preferred to "keep things light" and became upset when family members showed strong emotions (e.g., crying) in her presence. Therapy provided a safe space for her to explore her thoughts and emotions around this and build her tolerance in "sitting with discomfort." Meanwhile, I worked with Marie's parents on ways that they could communicate with Marie and normalize difficult emotions for her.

Like many loving caregivers, Marie's parents wished to protect her from further distress and receiving "bad news." As part of a team effort, I proceeded with the delicate task of learning about Marie's and her parents' respective communication preferences and helping them navigate conversations in a manner that felt tolerable, honest, developmentally appropriate, and consistent with their values. I provided psychoeducation about ways that sharing information can reduce anxiety, and we discussed how families rarely regret having these conversations. Relatedly, it was important to provide Marie opportunities to confront her fears about dying since she was fully aware of her worsening cancer. While Marie was steadfast in her hope that the next step "would work," she also spoke about death indirectly by referencing "my time left" or voicing concerns about her pet's lifespan. With normalizing education to Marie that many kids find it helpful to share their choices in case they ever get too sick to name them later, she completed multiple components of the My Wishes planning guide, specifying things that comfort her, preference for location of death and visitors, beliefs about what happens when a person dies, and what she would want her death to be like. After this session, Marie bravely chose to share these preferences with her parents.

Marie's cancer continued to progress, and her family courageously decided to transition her care to home hospice. Psychology follow up was increasingly flexible and sessions were brief as Marie's condition worsened. Marie was comfortable and regularly denied anxiety. Even though it became hard for her to talk, she benefited from guided imagery to promote comfort and smiled in response to imagery scripts that were tailored to her own life. There was close collaboration with the palliative care team during this time. My role involved collaborative problem-solving, reinforcing the family's coping and choices during this impossible time, and provision of emotional support. Marie died peacefully surrounded by family.

Conclusion

Pediatric psychologists' breadth of skills adds incredible value to PPC. As part of the interdisciplinary team, they contribute to PPC innovation through research, assessment, intervention, program development, interdisciplinary collaboration, and advocacy. Psychologists' involvement in PPC is critical to ensure pediatric patients with life-limiting illness receive the highest quality clinical care.

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Suggestions from Child Life Specialists to Improve Care of Children, Teens, and Families

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Death is stupid but the grief journey can be a memorable and impactful healing process. This is why children and families need support and tools to help them cope.

Children and teens may respond to death differently than the way adults expect them to which can lead to confusion, fear, and anxiety. As parents and caregivers, our instinct is to protect our children, and we often respond by limiting information or not sharing what is happening. Our goal is that by sharing this information and with proper support and encouragement, parents and caregivers can better understand the importance of end-of-life communication. Our hope is that parents and caregivers will learn to accept grief as a normal life experience and be open to the idea that coping skills can be learned, and healing will happen.

Research shows that withholding information can make a child or teen's grief journey more difficult. When children and families are given information in a supportive and developmentally appropriate manner they can learn to develop healthy ways of coping.

There are many great resources available and having a support system during end-of-life experiences can be helpful. One of the healthcare professionals that help children, teens, and families navigate bereavement and grief is a Child Life Specialist.

A Certified Child Life Specialist (CCLS) is someone who works with children, teens, and families during their grief and loss journey. Certified Child Life Specialists are unique clinicians that often no one knows about until they meet them. Families quickly recognize the positive impact that working with a CCLS can have during difficult times. A CCLS is a degreed professional trained in providing psychosocial care and has the expertise and skills to help children, teens, and families process and understand their feelings and actions. Everyone has a history; everyone has experiences that shape them into who they are. CCLS's often work with families and the medical team to assess coping from a psychosocial and emotional safety approach to ensure that families feel holistically and completely cared for. As a CCLS, we embrace the difficult and uncomfortable, we ask the questions and use play so we can better understand how a child's thoughts and feelings make them think, act, or interact with others. We hear from children and teens that death is stupid, and they are not wrong! Death is hard, it brings up so many emotions in all of us and how we process and deal with those emotions often indicates how we will move forward through the grieving process. Death, loss, and grief do not have a logical guidebook or clear rules, but we know that providing developmentally appropriate information, safe outlets, opportunities to express feelings, and modeling positive coping skills can offer a better path for healing.

Providing developmentally appropriate information is important because children and teens understand death differently and the goal is to help them process and understand at their developmental level.

Younger children see death as reversible and may keep asking when the person is coming back. They may start playing right after they are told a loved one died. Play is what children know, it is familiar, and how they learn; it is ok for children to behave this way.

Children around the age 7 – 11 start understanding that death is permanent. They may ask questions about what happens to the body when it dies. Graphic details are not necessary, simple explanations such as, the heart stops, the brain no longer works or thinks, body does not move, organs no longer work; the lungs no longer breathe, are some of the best ways to explain to school age children. Explain that sometimes, not always, diseases/illness affect people in these ways. When someone is involved in an accident these things in our body cannot always be fixed.

Teens may often ask more detailed questions, and it is important to be factual and concise when providing answers and to check in to make sure they understand or if there is a need to ask more questions.

Common reactions to grief:

Infants and toddlers – may have changes in sleeping routines, regression (pacifier or bottle use, bedwetting), and separation anxiety. Children learn through play, so they may pretend their toy has died—this is part of processing and attempting to understand death and helps them work through their feelings.

Preschoolers – are magical thinkers and sometimes their imagination can make situations worse than they are. Talk to them about the situation and clarify any misunderstandings. This age group is egocentric, meaning all things revolve around them, and they may blame themselves for the situation that happened or death. For example, if I would've eaten dinner last night, like I was told, this would not have happened. This age group may also hear things literally, be careful when using words that have double meanings such as: "rest in peace," "they are sleeping," "passed away," etc. They may have regressive behaviors such as: talking like a baby, clinginess, bedwetting, temper tantrums, and may also have nightmares. They may be frightened about the concepts of burial and cremation as they do not understand the permanence of death.

School age – beginning to have an understanding regarding the permanence of death. They may show anger towards the person who died, might participate in more aggressive play, and may have nightmares.

Teens – often feel out of control when they experience the loss of someone they loved. This can be overwhelming or frightening. Teens respond to grief depending on different variables: the cause of death, who died (sibling, friend, parent), relationship to the person who died, previous experiences with death, and maturity level. Teens may withdraw from activities or social events and isolate themselves more than usual. Teens may be afraid to share their feelings with the ones they are closest to with fear of upsetting them. Remember to encourage families to talk about death, support and validate whatever feelings are being exhibited, offer words of encouragement, and maintain safe behaviors.

These are some additional ways to help children and teens process their grief and learn how to cope:

- Encourage open, factual, and concise communication
- Talk to your child's teacher or counselor at school to let them know what is going on
- Listen more, talk less
- Provide safe outlets like play, sports, music, art, journaling to help them express themselves
- Keep their routine as normal as possible
- Help children preserve or create memories: picture book, t-shirt pillow or quilt, decorate a
- frame, make something for the garden, write a poem, make a scrapbook, celebrate their birthday
- or special events, and remember and share your favorite memories
- Offer choices and set appropriate limits
- Give children the opportunity to attend the funeral and if they choose to go, prepare them
- Give them the opportunity to draw a picture or write a letter to the loved one that died
- Look for misunderstandings and miscommunications, correct, and answer honestly.
- Talk about the person who died, share memories. Celebrate the life!
- Teach kids about grief, how to understand what they are feeling and why, and teach them ways to cope. If they are having a difficult day, feeling sad, angry, or maybe even feeling guilty for being happy. Validate that what they feel is ok and talk about it.
- Teach them about what behaviors are ok and not ok, safety is important and making bad or reckless decisions is not ok.

- Reading a developmentally or age-appropriate book can be helpful to parents/caregivers/family to begin a conversation and help explain death, grief, and feelings.
- Use resources and support systems—people want to help, no one should feel they are alone.
- Asking for help is a strength, reach out when you need it!
- Churches, schools, community organizations, counselors, Children's Hospitals, and grief centers are a few places to look for resources and support.

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Energy Healing Work With Qigong: An Integrative Therapy

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Background:

My path to involvement in use of medical Qigong in the pediatric population was unusual. After being rear-ended in my auto twice, chronic muscle spasms and low back pain led me to learn and practice self-healing with Energy Work in 1998. Medical treatments had not healed me, and I prefer avoiding pain medications. Finally, I found a natural way to feel better! Medical Qigong (pronounced ‘chee-gong’) is the Energy Work I practice. Consistent daily practice healed my back pain, exponentially improving my quality of life.

A vital law of science states that though energy cannot be created or destroyed, it can be transformed. As a Master Instructor/Master Healer, I teach self-healing (internal qigong)—energy transformation techniques—and provide holistic healing support (external qigong) to people and animals of all ages, in all stages of health.

Medical Qigong is considered an internal, medical martial art. With this focus, I opened Wonder Horse Healing in 2011. We each have the power to transform our personal energy for the better. I have seen or experienced thousands of such transformations. Feedback received is consistently positive and powerful regarding the support I provide, and the healing progress made by clients and students using these tools. For nine years, I have held a Monday morning Qigong for Health class weekly. Now called Qigong for Women’s Health, women ranging in age from 24-89 practice qigong self-healing for a more vibrant life, in a supportive community.

Before ‘The Home’:

I have been a grateful and enthusiastic member of the Crescent Cove Integrative Therapies Team for nine years. I signed on as Qigong Therapist three years before the 2017 opening of Crescent Cove Respite and Hospice Home for Kids in Brooklyn Center, Minnesota. Before the opening, Qigong Healing Therapy was provided to children with life-shortening illness and during the end of their lives at home, in hospitals, and at Ronald McDonald House. Some in-home visits included whole-family group Qigong sessions, or bereavement support. In addition to Qigong comfort for children during illness, end-of-life, or hospitalization for surgery, Healing Support is available to the child's family members, friends, caregivers, and Crescent Cove nursing students, volunteers, administrative and clinic staffers—all who touch the child's life.

Support for people and animals:

Medical Qigong (from Traditional Chinese Medicine - TCM). Energy Healing Support (with minimal - or no - touch) includes Energy Healing Work sessions to support relaxation, better balance, breathing, cognition, pain/stress relief, and optimal healing. Primarily used with Crescent Cove's high acuity children, one's who are sleeping or unable to consent to touch. Qigong is unintrusive and appropriate for those who have experienced trauma and may have PTSD. Qigong energy healing can be effectively "applied" to humans and animals whether they are focused upon the healing work or not. Children can sleep or play, adults can work or rest, animals can "animal." Only the practitioner must focus on guiding the energy in and for recipients. *Children and animals are exquisitely receptive!*

Qi~ssage™ (pronounced "chee-sahj") Healing Support (with touch): For those able to communicate preferences and consent. Energy Healing is conveyed into and through the body using acupressure applied in a specific protocol from head-to-toes. The recipient remains comfortably seated and fully clothed. The positive effects of Qi~ssage™ are like Qigong, plus the benefit of compassionate, person-to-person connection through gentle, therapeutic touch.

Empowering Conversation (compliments above services when developmentally appropriate and time allows): Learn client's top challenges/goals, pain/stress levels; Demonstrate simple concepts and gentle, healing movements to expedite self-healing; Fine-tune language to optimize healing effects and goal advancement; Spiritual support.

Crescent Cove:

Each week, I receive advance information about Crescent Cove guests. Integrative Therapy Practitioners may work on different days from each other, so a child can receive a variety of therapies. We coordinate with on-duty staff regarding how our work fits into the flow of the day: who to serve, and when. For my work, children and family members are the priority, then staffers, volunteers, and nursing students. Information provided by parents and updates by staffers informs me of children's needs and preferences around level of interaction, communication, and touch. In 2024, Crescent Cove updated the title of my service (of integrative therapy options) to Energy Work, to convey that touch isn't *required*.

I find some kiddos engaged in activities with a staffer or reading, playing, enjoying music, walking, or swinging. Others are quiet, relaxing, or napping. Physically active children require that I follow them "on the move" in or outdoors. My flexibility and responsiveness are key since there is no typical child or session. I love that! Opportunities arise to work with Crescent Cove staffers and supporters in need of healing support (including bereavement) at their home, by telephone, or by online video visit.

Staff training days and retreats for Crescent Cove may include individual Energy Work sessions throughout the day or at the day's end. It would be difficult to identify which work (the who, what, when, and where) is most fulfilling. I truly love working with the 'family' that is Crescent Cove in all its robust goodness and grace.

Claire

On January 1, 2025, I worked with Claire, an 18-year-old respite guest. Claire's "Get to Know Me" sheet (which a parent completed) stated that she loves massage. I was happy to integrate customized Qi~ssage™ into her session, working her accessible areas: hands, feet, face, and head. Guests who cannot hear or speak can convey what they enjoy—or don't. Though it helps when practitioners tune in for subtle cues, Claire was clearly delighted to receive caring, therapeutic touch as part of her Energy Work. Her expression in this photo reflects that she's in "seventh heaven," blissfully relaxing and receiving. *The honor of being a part of the Integrative Therapies Team is a joy to me!*

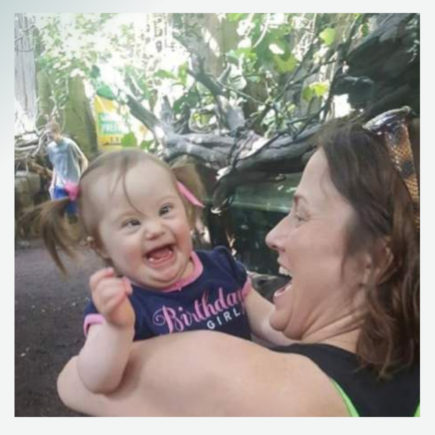
Harley

I worked with a respite guest, a young man named Harley in late 2023. He said that he would be happy to get Energy Work if he could keep doing homework. Grateful for his trust, I learned about his areas of discomfort and proceeded. He reported pain relief when the session was done. I worked with other respite guests and was called back to Harley's room. He was with his dad, and they were both ecstatic to tell me that, after suffering with a smirk "frozen" on his face, Harley smiled for the first time in six years after Energy Work! What a thrill! I saw him again, six months later. Harley was still smiling and enjoyed another Energy Work session. We marveled about qigong's power while I worked, and his neck pain resolved. Now a "qigong enthusiast," he let me teach him brief, guided imagery to use to relieve his pain any time he needs. It is a thrill to share our story about *the joy of cultivating more smiles in the world.*

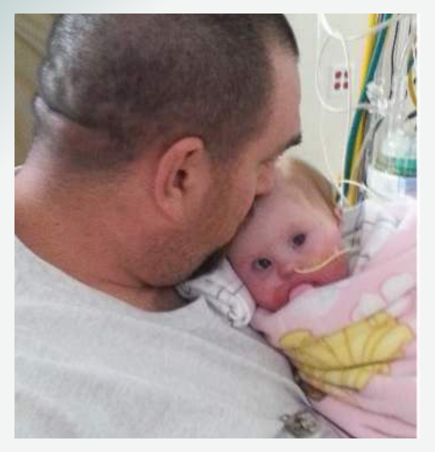
Before Energy Work was my profession, I enjoyed five decades of varied work: independent door-to-door sales, hospitality industry positions, cosmetology, retail and wholesale business ownership, working with animals, and nonprofit management/serving Minnesota elders. Qigong Energy Work, Qi~ssage™, and Empowering Conversation, Training and Managing Teams of healers are the most fulfilling.

Energy Healing Work recipients are consistently more comfortable, relaxed, and refreshed by Energy Work and its natural, holistic approach. Children with low muscle tone may experience improvement evidenced by relief from constipation during or shortly after a session. Mouth secretions may increase as the body's healing response is *appropriate clearing*. There are often comments from a staffer or volunteer who was working with a child prior to Energy Work, such as "This is the happiest she's been all day!" or "He is far calmer and more snuggly."

Serenity Rose & Her Family



My initial visit was to this family's hospital to support them after Serenity's surgery to repair heart defects associated with Downs Syndrome. I introduced myself to parents Janell and Matt, and learned their top concerns and priorities (body, mind, and spirit). I worked at Serenity's bedside using qigong healing support techniques to balance the energy flowing in (and around) her body to support her comfort and optimal recovery, while Janell shared observations about the hospital experience. Next, I worked with each parent in another room with the hands-on healing support of Qi~ssage™. They reported stress, tension, and pain levels were significantly reduced or eliminated.



For many months, I continued to work with this beautiful family, helping them cope with the stresses of Serenity's health conditions. Her parents were better able to cope, and not so tired or overwhelmed because of our sessions. Often, dear Serenity played with toys on the floor. She would stop when I arrived to smile and wave her arms in gentle circles, doing qigong. She felt, remembered, and knew why I was there. We loved that so much! Also, when I did Qi~ssage™ for her parents, she would often assist me—getting right in there! She was such a natural! I was honored to be of support during and beyond Serenity's life, sudden illness, and death in 2018.

Read Serenity's family Crescent Cove 'story page' here: https://www.crescentcove.org/why-we-do-it/kidsandfamilies/meet-serenity

The Value Of Joint Visits In Community-Based Pediatric Palliative Care

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When a child is diagnosed with a serious, life-limiting illness, the impact is profound, extending far beyond the child's immediate medical needs to affect the entire family system. Families must navigate not only the physical demands of the child's care but also the emotional, mental, spiritual, and social challenges that arise during this difficult time. The palliative care interdisciplinary team, comprising of doctors, nurses, social workers, chaplains, and other specialists, plays a critical role in addressing the multifaceted needs of both the child and their family. However, while the expertise of each discipline is invaluable, the revolving door of visits from multiple specialists can become exhausting and overwhelming for the family during an already challenging time.

The goal of pediatric palliative care is to provide a supportive framework that alleviates some of the stressors that the patient and family experience. To achieve this, a thoughtful approach to creating a family-centered care plan is essential, ensuring that the frequency and delivery of services are balanced to promote well-being. Through years of experience in community-based pediatric palliative and hospice care, our pediatric care team has found that joint visits where multiple disciplines collaborate in a single visit, offer a more comprehensive and integrated approach to care. Joint visits reduce the burden of constant appointments while also ensuring that the complex needs of the family are met.

Collaborative Care: Nurses, Social Workers, and Beyond

Joint visits between nursing and other specialists offer a holistic approach to care. For example, a nurse-social worker joint visit allows each professional to contribute their expertise in a complementary way, enhancing the experience for both the patient and family. In situations where difficult conversations are necessary, such as when a patient's condition worsens or a medical decision needs to be made, the nurse can provide the clinical education, while the social worker can ensure that the family fully understands the medical information and can address any emotional or psychosocial concerns.

Family dynamics can present additional complexities when these difficult conversations are needed. A nurse may observe resistance from families when discussing medical changes or suggested interventions for their child. This may stem from underlying cultural beliefs, fears, or misunderstandings. With joint visits, social workers can work alongside the nurse to explore underlying factors, offering support and addressing the family's unique preferences and needs. Similarly, a joint nursing visit with a chaplain can provide valuable insight into decisions regarding medical choices and goals of care. The chaplain can offer compassionate spiritual guidance to the decision-maker, helping them feel supported without judgment. In each of these ways, joint visits help break down barriers, ensuring that families feel heard, understood, and supported.

The Role of Music Therapy

The inclusion of music therapy in joint visits can further enhance the overall experience. Music therapy creates a therapeutic atmosphere that reduces stress and provides a sense of routine and normalcy for both the pediatric patient and the family. When pediatric patients are reluctant to engage in medical assessments, music therapists can assist by using techniques that prompt or distract the patient, helping to complete necessary nursing assessments with less resistance.

Music therapy can also ease anxiety related to medical interventions, such as venipuncture or lab draws. By incorporating soothing music and relaxation techniques, the music therapist helps reduce the emotional and physical trauma often associated with the medical procedure. This not only benefits the pediatric patient but also helps family members cope with the distress of watching their child undergo such procedures.

Child Life Specialists: Supporting the Whole Family

Normalization, play, preparation, child development education, and support are the core building blocks of child life work in both hospital and community-based settings. Child life specialists use play and developmentally appropriate techniques to help children cope with the fear and anxiety that medical procedures often bring, as well as to normalize the overall experience. For example, a child life specialist might use familiar toys or stories to help the child understand what is happening and alleviate any confusion or distress.

In addition to supporting the patient, child life specialists also work with siblings, who often experience emotional distress as they witness a sibling undergoing medical treatments. By offering coping tools, emotional support, and space for siblings to express their feelings, the child life specialist helps to ease the emotional strain on the entire family system. This comprehensive support creates a more balanced and nurturing environment for everyone.

When nursing visits are paired with a child life specialist, families gain additional support in managing potentially distressing situations, while nurses receive help in accomplishing medical tasks. Child life specialists can assist in preparing the child emotionally for the visit, making it easier for the nurse to complete necessary assessments or procedures with the child more at ease. They can also work with the sibling while the nurse is seeing the patient, ensuring that the sibling's emotional needs are met alongside the patient's care.

Child life interventions can also be augmented with music therapy, adding another layer of therapeutic support. Music therapy offers auditory soothing and distraction that complements the emotional and physical support provided by the child life specialist. For example, music therapists may use calming sounds or songs as part of the relaxation techniques taught by the child life specialist, helping to reduce anxiety and promote a sense of comfort. This combination of interventions enhances the overall experience for the pediatric patient, helping them feel more at ease and less fearful during challenging moments.

When Joint Visits May Not Be Useful

While joint visits offer numerous benefits, there are times when they may not be the most effective approach. For instance, consider a scenario where a social worker needs to provide anticipatory grief counseling to a family. This type of session is deeply emotional and requires space for the family to process their feelings without distractions. If a joint visit is scheduled with a nurse, the focus may shift to medical discussions, such as the patient's current condition or treatment plan, which could inadvertently minimize the emotional space needed for grief work. In one particular case, a social worker was providing anticipatory grief counseling to a mother who was preparing for the imminent death of her child. The nurse was also present to discuss medical updates, and the mother found it difficult to engage emotionally, as her attention kept being pulled back to the medical information. In this case, a separate visit would have allowed the social worker to focus entirely on the emotional needs of the family without the interference of clinical discussions.

Additionally, coordinating schedules between team members and families can be challenging, and when joint visits occur, individual goals for each discipline may not be fully achieved. For example, during a music therapy session, a therapist may be working with a patient to reduce anxiety through soothing music. However, if a nurse or social worker is present for their part of the visit, the time for music therapy may be shortened, limiting the therapist's ability to fully engage the patient in the therapeutic process. In such cases, scheduling separate visits may ensure that each discipline has the time and space to meet their goals effectively.

Conclusion: A Collaborative Approach to Care

Joint visits provide an integrated, holistic approach to pediatric palliative care, meeting the diverse needs of both the patient and their family. By bringing together the expertise of nurses, social workers, music therapists, child life specialists, as well as other disciplines, we can ensure that families receive not only the medical care they need but also the emotional and psychosocial support that is essential to their wellbeing. These collaborative visits help reduce the burden of multiple appointments while offering more comprehensive, coordinated care.

The integration of joint visits into pediatric palliative care models should be considered a best practice, as it can significantly improve family satisfaction, reduce stress, and enhance the overall quality of care. However, it is essential to utilize clinical judgement and recognize that there are times when individual visits may be more appropriate to meet specific needs, ensuring that each discipline's goals are fully realized. By continuing to explore innovative ways to collaborate across disciplines, we can ensure that pediatric patients and their families are supported in the most holistic, compassionate way possible during one of the most challenging times in their lives.

Home is Where the Heart IS Sharing in Care of a Loved One

When Family Focus as the Interdisciplinary Team & Outpatient Palliative Care Offers Support with Pain & Symptom Management

By: Judy Zeringue, MAPL, BSN, RN, CPLC, CHPPN

This article and prayer, are dedicated to Jamie, my loving sister and best friend! She is an incredible inspiration and loved by many. In the face of this difficult challenge, she meets each day with faith and determination. I was honored to share in compassionate care for Jamie with her loving family.

To witness faith, courage, strength, determination, and unconditional love, in the face of pain and suffering, is very humbling. Our beloved, Jamie was an inspiration to live each day to the fullest, often sharing her beautiful smile! She experienced renal cancer with metastasis to the spine and significant pain. Taking nothing for granted, we embraced each day with gratitude, for this sacred time together, sharing moments of joy and unending love.

Despite progression of a life-limiting illness, hospice support through her insurance company only honored 180 days per calendar year for hospice benefits. How can it be that coverage for hospice stops, despite progression of the disease process and certainly meeting eligibility criteria? Appeals may be possible with great distress in the process while paying out of pocket at an exorbitant cost. To align with the wishes our our beloved, we quickly shifted to outpatient palliative care support for pain and symptom management from our family home interdisciplinary team. Per Jamie's wishes, she desired care at home to intensively focus on comfort and quality of life.

Palliative care is a great support, both inpatient shortly after diagnosis and when called upon as an outpatient team to provide pain and symptom management from our family interdisciplinary team to care well for our beloved.

Respecting the dignity and wishes of those with a life-limiting illness is essential. Discussing goals of care and determining what is most important to them can guide caregiving. When aggressive palliative treatment is no longer the desired plan, an individual may choose to intensively focus on comfort and quality of life. Advance directives were completed to clearly outline desired wishes for medical care when death approaches.

Jamie experienced significant pain due to her metastatic cancer which has resulted in bone fractures in the spine. As the disease progressed, it was imperative to continue with excellent pain and symptom management. When hospice stopped, we immediately sought the services of an excellent outpatient palliative care doctor who could help us to mitigate the pain and suffering while we helped Jamie focus on quality of life.

As a family, we efficiently served as an interdisciplinary team. Her husband lovingly was the primary caregiver and was with her daily. As hospice ended due to insurance time limitations, equipment was removed from home and quickly assessed to obtain those things needed to assist with comfort and quality of life. One daughter, a nurse focused on meticulously setting up all medications for the week. She requested refills as needed and offered support on a daily basis as needed. We all knew the med schedule and assured meds are given. PRN's were listed on a board on the refrigerator to maintain communication of additional meds given. Another daughter, provided loving emotional support through daily phone calls and special visits. As a loving sister, I was blessed to share in care during this sacred time. Through a lens of nursing and spiritual care, as well as a passion for palliative and hospice care, I have been able to use these gifts well to assist in care. Together, we have been able to offer one another love and support. As each of us noted a need, we simply communicated and ordered those special supplies or equipment to make the days a bit better. The family dogs offered daily pet therapy, while we incorporated emotional support and unending love and compassion. Nursing care, spiritual support, lots of art & music therapy were provided, as well as aroma therapy with favorite soaps, lotions, and sprays. We allowed Jamie to let us know what she was up to for the day. A variety of foods & desserts was offered, protein supplements, coffee topped with whipped cream and lots of chocolate that she enjoyed! On days when her appetite was not good, we offered a protein shake. but ultimately her decisions were respected.

Sharing in care for a loved one is a sacred honor. Family serving as an intricate interdisciplinary team can be emotionally and physically exhausting at times. For this reason, attention to self- care is essential. Take good care of yourself so you may be able to compassionately offer care and support with love. Everyone is unique, so find what fills your soul. Perhaps an outing to a movie with family, shopping, playing guitar and singing, time spent outdoors, exercise or quiet time in prayer. Strive to get adequate rest and healthy nutrition. Be sure to attend to your own health needs and you will be better able to care for those entrusted to your care.

Care in the comfort of home was an expressed desire per our beloved. Cared for by compassionate loving family, to promote relief of pain and symptoms with focus on quality of life. Our beloved has great faith, a beautiful smile, and deep love for family and cherished friends. Daily pet therapy was provided by two attentive and loving pups. We enjoyed attending weekly Mass, many outings with family and friends, cherished time at home, endless phone calls of loving support, lots of crafts, painting, and diamond art. Watching movies, cooking shows, and competitions filled our days, along with staying attentive to all of her family and many supportive friends. Periods of rest allowed for the energy to do what was most important for Jamie each day. Sharing in meals and visits was accompanied by appreciation for each and every day, as well as support with much love and many prayers. We embraced each day with gratitude for this sacred time together, and we shared moments of joy each day!

Prayer for Our Beloved

Dear Heavenly Father,

We know that you are here with us. Surround us with your love. Give us courage, perseverance and reassurance to trust in your plan. Allow us to see with eyes of faith. Help our faith to be stronger than our fears. Allow us to feel your loving embrace surrounding us and know that you are with us and support us on this journey.

Entrust us to those who lovingly provide compassionate care. We humbly request to see with eyes of faith, beyond our present moment and grant us your peace, beyond understanding.

Allow us to embrace each day, finding moments of joy. Grant us the understanding to feel the love which surrounds us and offers support from near and far. Family and friends send love and prayers to share deep love and compassion. Let these prayers and heartfelt love, warm our hearts and ease our minds to bring us peace within.

All these things we humbly ask through Christ, our Lord, Amen!

“My grace is sufficient for you, for my power is made perfect in weakness.” 2 Corinthians 12:9

Addendum: After completion of this tribute, Jamie died in comfort and peace at home surrounded by her loving family on January 6, 2025. May she rest in God’s peace and forever remain etched in the hearts of those who love her so dearly.

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.

- **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 #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 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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