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HOW CULTURAL OR RELIGIOUS DIFFERENCES AFFECT CARE

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Issue Topic: How Cultural or Religious Differences Affect Care

Welcome to the 84th issue of our Pediatric e-Journal. The focus of this issue is on topics related to cultural or religious differences and how they affect pediatric hospice and palliative care. Cultural and religious differences are often deeply imbedded in the children, adolescents, and family members we serve, not to mention the professionals and volunteers who provide such services. In addition, they are the special province of chaplains and other clergy who help to provide pediatric hospice and palliative care.

Even a full issue of our e-Journal cannot expect to be sufficient to address these subjects in a comprehensive fashion. However, by opening discussion of these topics in this issue, 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 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 allianceforcareathome.org/pediatric-e-journal

Comments about the activities of the Pediatric e-Journal Workgroup or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Our

tentative plan is for Issue #85 is to focus on the current state of affairs in pediatric hospice and palliative care. We have some ideas for Issue #86 and beyond, but we are open to suggestions concerning topics for those issues. If you have any thoughts about topics or other subjects for future issues, as well as for 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 our 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.

Produced by the Pediatric e-Journal Workgroup.

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This article proposes that, "Spiritual care is a necessary and often complex component of palliative care, and encompasses what gives people meaning and how they experience their illness and relate to others…Thus, clinicians must recognize and honor the importance of spirituality in pediatric palliative care and continue to explore these concepts through ongoing clinical care and research." In particular, the article addresses components of spiritual care and assessment, as well as identifying spiritual issues.

Spirituality and Nursing Care **p. 5**
Sarah Bone Schroyer, DNP, RN, CHPN, NE-BC, CNE

Taking nursing care as its paradigm, this article notes that "spirituality in pediatric hospice care is broad and deeply personal." Spirituality as it is experienced by parents, children, teenagers, and others involved in pediatric hospice care can be shared in diverse ways with nurses at the bedside and everyone else who delivers this type of care. The article concludes in this way: "At its heart, spiritual support in pediatric hospice is about honoring the full humanity of children and families. It is about recognizing that serious illness raises questions that cannot be answered by clinical expertise alone. Children and families need skilled symptom management, but they also need presence, meaning, connection, and the reassurance that they do not have to carry their suffering alone."

Can Faith Meet Science? What Research Suggests about Faith as a Coping Tool when Illness Affects the Family **p. 9**
Emily Roff, Ed.D., CCC-SLP, BCBA

"[T]he aim of this article is to share the exceptional evidence science has provided that squarely places spirituality as a key factor of the healing and coping process." To be more specific, the author asserts that "The research on spiritual practice in health care repeatedly concludes that not only spiritual practice but, more specifically, religious practice…can be a hugely mitigating factor, lessening the negative effects of caregiver strain on those helping the chronically ill." She concludes that "it is the hope of the author that if anything is taken away from this article, it is that—All is not lost. Regardless of your current circumstances, grief does not need to become the new norm. If one is brave enough, even the most skeptical and discerning of souls can embark on a beautiful and meaningful journey of hope, gratitude, and joy, through the pursuit and practice of faith." The article concludes by offering brief suggestions about how to start in pursuing a faith-based journey and some inspirational readings from sacred texts.

Spiritual Care in Pediatric Hospice and Palliative Care **p. 15**
Cristina "Cristie" Florido, APRN, FNP-BC, and Rev. Travis Greene, MDiv, BCC

These authors begin from the premise that "Children who suffer from serious illness (and the families who care for them) often navigate profound emotional, spiritual, and cultural experiences throughout the course of illness, end-of-life, and bereavement—they should not do it alone." The authors then offer a description of what spiritual care means, an account of James Fowler's Stages of Faith Development, and a story of spiritual care and companionship.

Chaplains, Children, and Families **p. 21**
Chaplain John C. Fitts

In this article, the author of the inspirational "Grace Drops" blog describes his transition from serving for 18 years as a church pastor to becoming a chaplain in a children's hospital. As a church pastor, he had been involved in many traumatic events; as a new hospital chaplain, he describes what he learned from a Clinical Pastoral Education course which began what he terms "a journey of self-discovery" and led to involvement in s hospice program. The lessons learned are illustrated by numerous examples.

From Lives Remembered to Lives Interrupted: The Sacred Transition from Adult to Pediatric Hospice Chaplaincy **p. 24**
The Rev. Orlando J. Addison

This article describes "what happens when chaplains move from caring for adults to working with children in hospice." The author offers examples of how moving to pediatric hospice chaplaincy altered him. As he writes: "In adult hospice care, there's this sense that everything is supposed to come full circle. Chaplains help people tie up loose ends, repair relationships, ask for forgiveness, and look back at a life with some kind of meaning…But pediatric hospice just shatters all that. It doesn't let life play out to a natural ending. It stops everything, too soon, too suddenly. Chaplains walk alongside families who aren't just losing their child; they're losing every hope and dream tied to that child. Birthdays that will never happen. Milestones that will never come. Stories stuck at the start." His observation in the context of pediatric palliative and hospice care is, "You can't fix this by just rewording things. The whole way of thinking about care has to change. The chaplain has to leave behind that idea of completion and step into a world where the pain won't wrap itself up neatly. Meaning gets hard to find. Sometimes, all you can really offer is your presence, just being there, without answers or easy resolutions." The article concludes with comments on these topics: The Theology of Mystery and Lament; Incarnation and the Presence of God; Silence as Pastoral Practice; Family-Centered Spiritual Care; Re-imagining Hope; The Chaplain's Transformation; and this observation: "If adult hospice proclaims, 'You are coming home,' pediatric hospice bears witness to a different, yet equally sacred truth: 'You are not alone—not now, not ever.'"

Never Alone: The Role of Spiritual Support in Pediatric Care **p. 29**
Pastor Josh Skjoldal

Picking up a point from the conclusion of the previous article, this author observes that while it is "never easy, it is a privilege to be a stabilizing force in the midst of uncertainty." As he adds, "Crisis reveals a need." In this context, "Spiritual support in pediatric care must be clearly defined so it is not misunderstood. It is not proselytizing, pressuring families toward a particular belief system, or leveraging vulnerability for religious persuasion. It is not a replacement for medical expertise, nor is it a denial of clinical reality. Spiritual care does not minimize diagnoses, dismiss grief, or offer false certainty. Instead, it provides space for the formation of hope while anchoring people in the midst of uncertainty. It helps children and families interpret suffering without being defined by it." This leads to comments on the following topics: The Necessity of Spiritual Care; Compassion Keeps You in the Room; Opportunities to Increase Support; Never Alone.

The Meaning and Ecstasy of Being a Pediatric Hospice Chaplain for Our Children and Families in Care with Capital Caring for Kids **p. 32**
Chaplain George Ryan

This article begins by noting that, "In supporting our families, the CCK [Capital Caring for Kids] chaplain does not judge ideology or religious practice before acting to support our families." Nevertheless, "The pediatric hospice chaplain has a unique position on the CCK care team. As the spiritual focus for the patients and the families, the chaplain is often designated as the religious person to initiate prayer, spiritual reflection, and application, as well as the officiant during religious ceremonies, such as memorial services." More to the point, the chaplain can help in developing "a realization by the families that the peace they seek is not attainable nor can it be sustained in their present circumstances." This involves "learning to surrender control to what cannot be managed. In the loss of control, the families are presented with a sacred pause, a chance to just be, a time to let God be God, by surrendering to God's unfolding plan." To achieve this, pediatric hospice chaplains use the method of prayer, "A prayer of being fully present and engaged in life…not a prayer of supplication or solicitation; not a spiritual regimen defined with ritual and abasement, but a prayer of surrender and the extreme response of laughter in communion with a loving God who knows what is best for us. This is a faith beyond all expectations and understanding. A faith of surrender. The type of faith that believes in God's mercy and the path of redemptive suffering to internal peace; the I Am of Scripture, who teaches what is best for you, a God who directs our way."

Bearing Witness: Pediatric Palliative Care in Amish and Mennonite Communities p. 38
Keturah Beiler, BSN, RN, CHPPN

This article, by a registered nurse and manager of a palliative care program in Pennsylvania, describes "how culture and faith shape the experience of illness, death, and caregiving within what are often referred to as the Plain Communities." The article begins by describing the author's arrival in a home in which baby Samuel, the 10th child in the family had recently died. As she explains, "In Amish tradition the body of a loved one is returned to the home and remains there as family, friends, and church members gather to support one another" and the home will be the site of the funeral. The larger context for this scene is that, "Because Old Order Amish and Old Order Mennonite individuals often generally marry within their communities, there is a higher prevalence of certain autosomal recessive genetic conditions. When both parents are carriers, there is a 25% chance with each pregnancy that a child will be affected...For many families, however, this risk does not deter them from having children. The value placed on family, faith, and community outweighs the uncertainty of medical outcomes." The author offers these two important comments: First, "In many ways, the goals of palliative care align naturally with the values of Plain communities: focus on comfort, the importance of family presence, and an acceptance of death as a part of life rather than something to be resisted at all costs. However, this alignment does not eliminate the need for thoughtful, culturally responsive care. It requires clinicians to listen carefully, to avoid assumptions, and to recognize that what defines 'good care' may look different in each cultural context." And second, "In that space, I was not the expert. I was a witness. And in witnessing, I learned that sometimes the most meaningful care we can offer is not found in what we do, but in how we are willing to be present, quietly, respectfully, within a family's sacred way of loving and letting go."

Spiritual Distress Manifested in a Teenager After a Stem Cell Transplant p. 41
Robin Bennett Kanarek, BSN, RN

In this article, reprinted by permission from the Journal of Pain and Symptom Management, a mother describes how her teenage son's thoughts and feelings were manifested in his atypical behavior when he was in strict isolation after a stem cell transplant. The important point is that these behaviors came to be understood as his spiritual distress. His mother believes that her son's story "highlights the importance and value of healthcare providers listening to a parent's perceptions of their child's state of mind. Atypical behavior could be a manifestation of spiritual distress and requires further assessment from the health care team." She describes her later efforts to create a foundation to educate healthcare providers about the importance of palliative care and its spiritual dimensions. She writes that the mission of the foundation is ''to improve the quality of life for those affected by cancer and other serious, life-threatening conditions through the promotion, education, and integration of palliative and supportive care into all aspects of health care.''

Perspectives of Spiritual Care in Pediatric Palliative Care **p. 45**
Judy Zeringue, MAPL, RN, BSN, RTSCBC, CPLC, CHPPN

This article summarizes the point of this issue of our e-Journal through its assertion that "A pediatric patient/family/caregiver's spiritual or religious beliefs may offer a source of strength or coping. It may affect decisions for the plan of care and may be important aspects to review to honor their wishes and hopes with end-of-life care." Because this is true, "Including a spiritual care assessment is an important component of viewing the whole person. To do this well, all team members may prepare themselves as Spiritual Generalists." The author writes that when "a deeper dive in Spiritual Care is needed, we can count on our valuable Chaplains who are Board Certified and specially trained for this focus of care and ministry of presence." In the meantime, she offers two helpful resources for all providers to improve their competencies in spiritual care.

Readers' Corner: Reflections through a Lens of Spirituality in Pediatric Palliative Care **p. 48**
Judy Zeringue, MAPL, RN, BSN, RTSCBC, CPLC, CHPPN

This issue concludes with a reflection on a book, Making Health Care Whole: Integrating Spirituality into Patient Care, by Christina M. Puchalski, MD, and Betty Ferrell, RN, PhD. The author of the present article highlights how the contents of this book can help providers achieve a richer understanding of what Dame Cicely Saunders called "total care." She emphasizes a quotation from this book that reads, "if you are not providing excellent spiritual care, you are not providing palliative care."

Items of Interest! **p. 50**

Spiritual Issues in Pediatric Palliative Care

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Introduction

Palliative care is a philosophy of care aimed at improving quality of life and reducing suffering for both adults and children living with serious or life-threatening illness through the identification, assessment, and treatment of physical, psychological, social, and spiritual needs (World Health Organization, 2020). Spirituality, as defined by the National Consensus Project guidelines, is "a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, transcendence, and experience relationship to self, family, others community, society, nature, and the significant or sacred" (Ferrell et al., 2018, p. 1687). Spirituality is expressed through beliefs, values, traditions, and practices, and is the "quest for meaning in human existence, especially in the presence of suffering and death" (Richoux & Zeringue, 2025, p. 429). Spirituality and faith can be complex, especially in children, and thus it is important to consider these aspects at each stage of a child's development as children may question their faith and the reason for their illness in an age and developmentally appropriate manner (Richoux & Zeringue, 2025). It is essential for palliative care clinicians to be present and engage in communication about spirituality with children (Ferrell et al., 2016).

Spirituality is considered an essential domain of palliative care, yet religious and spiritual coping remains understudied, particularly in children, despite children living with serious illness and their families often identifying religious and spiritual needs throughout the illness journey (Schaefer et al, 2025). Understanding a family's religious or spiritual beliefs and a child's unique spirituality is essential to caring for the "whole child" and is a necessary part of an individual's history as religious or spiritual beliefs may influence decision-making and coping (Richoux & Zeringue, 2025). It is known that attention to spiritual needs can have a positive impact on quality of life, however, clinicians often report a lack of confidence in addressing spiritual distress (Ferrell et al., 2023). Thus, it is important for palliative care clinicians to be aware of what spiritual issues may arise for children throughout their disease trajectory and to have a basic understanding of how to recognize and assess these issues in the pediatric population.

Components of Spiritual Care and Assessment

An essential component of palliative care and spiritual care is the development of compassionate and therapeutic relationships between clinicians and individuals living with illness and their family members. Spiritual care is centered upon relationship-centered compassionate care which allows for each member of the interprofessional team to offer "presence, deep listening, observing, and being with" (Richoux & Zeringue, 2025, p. 430). An important aspect of spiritual care is sitting in silence with individuals and listening empathically, allowing for an expression of emotions, and responding with sensitivity and a validation of one's feelings. Leaning in, building trust, and listening attentively is an essential way to connect with and offer support (Richoux & Zeringue, 2025). Asking people about their faith traditions and praying together, when that is a part of their personal faith tradition, may also be helpful and a way to instill hope (Ferrell et al., 2016). When working with pediatric patients consider that, aside from expressing themselves through words and conversation, younger children may also express themselves through other modalities such as art and play.

Spiritual assessment is an ongoing extensive process of evaluating one's spiritual needs and resources and can be conducted by a member of the interprofessional team (Muehlhausen et al., 2022), although a chaplain or spiritual care provider often conducts it, when available. Asking questions about an individual's or family's sources of strength, such as "What gives you strength?" can serve as a brief screening tool as well as directly asking about one's spiritual or religious beliefs (Richoux & Zeringue, 2025). Taking a spiritual history is also an important skill for any member of the interprofessional team and includes asking about one's beliefs, values, experiences, and practices in the context of coping with a serious or life-threatening illness (Taylor & Trippon, 2020). Spiritual history models also exist to help elicit a spiritual history and three widely used examples are the FICA model (e.g., Faith, belief, meaning; Importance or Influence; Community; and Address in Care), the SPIRIT model (e.g., Spiritual belief system; Personal spirituality; Integration with a spiritual community; Ritualized practices and restrictions; Implications for medical care; and Terminal events planning), and the HOPE model (e.g., Sources of hope; Organized religions; Personal spirituality or spiritual practices; and Effects on medical care and/or end-of-life issues) (Richoux & Zeringue, 2025). In pediatric palliative care, spiritual history is often discussed with parents or caregivers about the family's beliefs unless the child or adolescent is developmentally appropriate and wishes to participate in the conversation.

Identifying Spiritual Issues

The spiritual assessment and history-taking models mentioned above serve as useful frameworks to guide conversations with the families of children living with serious illness. However, it is impossible to predict the distinct and specific spiritual care needs of each individual and little is known about the specific spiritual needs of families (Ferrell et al., 2016). Some evidence exists that postulates that families cope by processing along three domains: life philosophy, which includes principles that guide decision-making and how the onset of a child's illness promotes a change in personal values; relational, which focuses on how caregivers perceive themselves (e.g., parent), others (e.g., their

child), and how they believe others support them (e.g., family, friends, providers); and transcendent, which encompasses God-related concepts, divinity and divine intervention (e.g., miracles and events that cannot be explained with scientific knowledge) (Miguel et al., 2024). Another study showed that families experience spiritual distress along the continuum of blame and regret, anger with God, and ritual and cultural traditions (Ferrell et al., 2016). It is also known that individuals faced with a life-threatening illness may struggle with feelings of loneliness, loss of hope or meaning, despair, and fear of death of their child (Wierstra et al., 2023).

While it is beyond the scope of this article to conduct an exhaustive review of the literature or fully explore all of the spiritual issues that children living with serious or life-threatening illness and their families face, it is important to recognize that children and families do identify religious and spiritual needs in the context of palliative care and experience spiritual distress. Religion and spirituality are an important aspect of coping for families (Schaefer et al., 2025) and factors such as a child's developmental age and stage and their parents' beliefs also influence how children view their illness and find meaning. Families often experience distress along a continuum and may have feelings ranging from anger or regret, finding new meaning, and seeking forgiveness (Richoux & Zeringue, 2025), all of which may influence how they make decisions about their children's care. Talking with families about their beliefs; listening empathically and allowing space; preserving hope for families; and honoring and respecting rituals and cultural traditions are all ways in which the palliative care team can provide supportive spiritual care (Richoux & Zeringue, 2025).

Summary

Palliative care aims to improve quality of life and reduce suffering for individuals living with serious or life-threatening illness and their families through the identification, assessment, and treatment of physical, psychological, social, and spiritual needs. Spiritual care is a necessary and often complex component of palliative care, and encompasses what gives people meaning and how they experience their illness and relate to others. A thorough assessment of children's and families' religious and spiritual beliefs is an essential part of palliative care assessment and spiritual history models are available to guide members of the interprofessional team in having these conversations. Although the ways in which children and families identify religious and spiritual needs differ, they globally report having emotions ranging from anger to meaning making to forgiveness and experiencing spiritual distress. Thus, clinicians must recognize and honor the importance of spirituality in pediatric palliative care and continue to explore these concepts through ongoing clinical care and research.

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Spirituality and Nursing Care

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When people think about pediatric hospice care, they often think first about symptom management, medications, and helping families navigate the practical realities of serious illness. Those things are certainly important, but they are only part of the work. Children receiving hospice care and the people who love them are also carrying questions that are much harder to measure. They may be asking why this is happening, what comes next, how to hold on to hope, and how to find peace in the middle of heartbreak. That is where spiritual support becomes such an important part of nursing care.

In pediatric hospice, spiritual care is not limited to religion, although for some families faith, prayer, clergy, or sacred rituals are central sources of strength. For many families, spirituality is also expressed through meaning, love, connection, memory, identity, and the desire to know that a child's life matters deeply. Nurses are often the ones closest to these moments. We hear the questions families may not ask anyone else. We notice the silence, the fear, the anger, and the longing for comfort. Even when spiritual care is not formally named, it is often present in the everyday work of hospice nursing (Cheng et al., 2024).

One of the most important starting points is understanding that spirituality in pediatric hospice care is broad and deeply personal. It can include belief in God, religious practices, or spiritual rituals, but it also includes the search for meaning, the need for connection, and the hope for peace. Ferreira and colleagues (2026) found that spirituality in children with life-limiting and complex chronic conditions is shaped by relationships, developmental level, normalcy, meaning, and purpose. That matters because if nurses think about spirituality only in formal religious terms, we may miss what a child or family is actually trying to express. A child may not ask for prayer, but may worry about being forgotten. A teenager may not use spiritual language, but may wrestle with identity, fairness, and what their life will mean. A parent may not ask theological questions directly, but may still be struggling deeply with suffering and hope. For nurses, that means spiritual care must be developmentally sensitive. It also means that listening carefully is often more important than trying to come up with the perfect answer.

Families are also experiencing spiritual distress, even if they never use that language. Parents may struggle with guilt, helplessness, unanswered prayer, and the painful tension between hope and reality. They may be trying to stay strong for their child while quietly questioning everything they

thought they understood about life, faith, or fairness. Siblings can carry their own burden of confusion, fear, resentment, or grief, and they are often overlooked in the intensity of the child's care. Research continues to show that siblings in pediatric palliative settings experience helplessness, isolation, uncertainty, and grief-like responses, which underscores the importance of intentionally including them in family support (Rajendran et al., 2024). In hospice care, the patient is never just the child. The unit of care is the family, and spiritual support needs to reflect that.

This is one reason nurses play such an important role. We are often present in the ordinary moments when deeper concerns surface. Families may not ask for a chaplain right away. They may first share their fear, sadness, or anger with the nurse at the bedside, in the home, or during a quiet conversation after a difficult day. That does not mean nurses have to become spiritual experts or have all the right words. In fact, some of the most meaningful spiritual support comes from presence, calm, honesty, and the willingness to stay with families in emotionally difficult spaces.

Spiritual support often begins with noticing. It may look like recognizing when a parent keeps circling back to questions of "why," when a sibling withdraws, or when a child expresses concern about what will happen to family members after they die. It may mean paying attention to what gives the family comfort, whether that is prayer, music, silence, story, ritual, or simply being together. It may also mean recognizing distress that is hidden under more practical language. A family asking repeated questions about treatment, for example, may actually be expressing fear, loss of control, or the struggle to let go.

Because of this, spiritual assessment does not always need to be formal to be effective. It can happen through gentle questions and attentive observation over time. A nurse might ask, "What has been helping you get through this?" or "Are there any beliefs or practices that are especially important to your family right now?" Other helpful questions might include, "What brings your child comfort?" or "What feels most difficult to make sense of?" These are simple questions, but they can open the door to much deeper understanding. At the same time, nurses should watch for signs of spiritual distress such as hopelessness, guilt, anger directed at God, family conflict around meaning, or a sense of disconnection from previously important beliefs or rituals (Brouwer et al., 2024; Cheng et al., 2024).

Cheng and colleagues (2024) described spiritual care in pediatric palliative settings as something perceived in "every detail," and that fits with what many nurses know from practice. Sometimes spiritual support is helping a family preserve a ritual that matters to them. Sometimes it is contacting clergy or chaplaincy. Sometimes it is helping parents shift their understanding of hope so that hope no longer has to mean cure, but can instead mean comfort, connection, peace, or meaningful time together. Sometimes it is simply sitting quietly and not rushing to fill the silence.

For children and adolescents, spiritual support may also involve creative and developmentally appropriate approaches. Drawing, music, storytelling, keepsakes, memory-making, and legacy activities can help children communicate what matters to them, even when they do not have the language to describe it directly. These kinds of interventions do not take away suffering, but they can create space for connection, identity, and remembrance.

One experience that has stayed with me involved a 15-year-old young man on hospice who told me he knew his death would likely come soon, even though his parents were not ready to accept that. It was October, and during our conversation he shared that his family used to make Christmas ornaments together every year. The year before, he had decided he was "too grown up" to participate, but now the tradition had taken on a very different meaning. It was no longer really about ornaments. It was about family, memory, and creating something that would remain after he was gone. I worked with the social worker to gather the supplies they needed so the family could have an ornament-making party together. That moment stayed with me because it was such a clear reminder that spiritual support is not always about formal conversations about faith or even about death itself. Sometimes it is about helping a child and family reconnect with what matters most while there is still time.

Interdisciplinary collaboration is another important part of spiritual support. Nurses are central to this work, but we are not meant to do it alone. Chaplains, social workers, child life specialists, bereavement coordinators, physicians, and community faith leaders all bring something valuable. At the same time, collaboration does not mean handing spiritual care off to someone else the moment it becomes uncomfortable. Nurses are often the first to recognize the need, begin the conversation, and help connect families to additional support. When spiritual care is well integrated, it becomes part of the overall plan of care rather than a separate or isolated service (Lee et al., 2024). My experience working with the social worker on that ornament-making project reinforced how meaningful interdisciplinary collaboration can be. Spiritual care often becomes most visible when team members come together around what matters most to the child and family.

Of course, spiritual care also requires humility. Families do not all believe the same things, and not every family identifies with religion. Some will draw deep strength from faith, while others may feel angry, uncertain, or disconnected from beliefs that once sustained them. Nurses must be careful not to impose their own perspectives or assume that what is comforting to one family will be comforting to another. Respect, curiosity, and cultural humility are essential.

There are also real barriers to providing spiritual support well. Time constraints, documentation demands, limited training, discomfort with spiritual conversations, and fear of saying the wrong thing can all get in the way. Many nurses recognize the importance of spiritual care but still feel underprepared to address it confidently. Parents caring for children with life-limiting conditions at home have also described barriers to receiving adequate spiritual support, especially when care systems focus more heavily on physical tasks than emotional or existential needs (Brouwer et al., 2024). This suggests that improving spiritual care is not only about individual nurse effort. It also requires organizational support, education, and a practice culture that values the whole person and the whole family.

That includes supporting nurses themselves. Nurses who regularly walk with families through the illness and death of a child carry their own grief, stress, and questions. Without support, that burden can contribute to exhaustion, compassion fatigue, or emotional distancing. Reconnecting with one's own sense of meaning and purpose can be protective, and organizations should make room for reflection, debriefing, and team support. Certain patients and families do stay with us. Their stories continue to shape how we think about care, presence, and what it means to accompany someone well.

At its heart, spiritual support in pediatric hospice is about honoring the full humanity of children and families. It is about recognizing that serious illness raises questions that cannot be answered by clinical expertise alone. Children and families need skilled symptom management, but they also need presence, meaning, connection, and the reassurance that they do not have to carry their suffering alone. Nurses are uniquely positioned to offer that kind of support. We do it when we listen carefully, notice what matters, make space for questions, support rituals and relationships, and remain present in moments when words are limited. In pediatric hospice, that kind of care is not extra. It is part of what it means to nurse well.

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Can Faith Meet Science? What Research Suggests About Faith as a Coping Tool when Illness Affects the Family

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Introduction: Parents, your dedication and sacrifice have not gone unnoticed.

Parents with a seriously-ill child (or loved one) rise to the occasion without question or hesitation. Their lives are upended as they struggle to find the best care and manage the complexities of the medical system and treatment recommendations. The overwhelming urgency of their situation often depletes them of vital emotional and psychological strength even while both are required to meet their most important goal, maintaining a smile on their child's face.

Rebuilding that oh so necessary strength sounds like an insurmountable task, right? Except wait—what if science is telling us otherwise? Remarkably, studies are showing us that spirituality may be the overlooked antidote to much of the negative emotional and psychological burdens of the caregiver. As such, the aim of this article is to share the exceptional evidence science has provided that squarely places spirituality as a key factor of the healing and coping process.

Why spirituality?

Researchers Kaye & Raghaven (2002) explain that spirituality is a personal view that expresses "a sense of relatedness to a transcendent dimension or to something greater than the self," which can then 'empower' or strengthen the self (p. 231). They contend it is spirituality that can transcend the "physical, emotional, intellectual, and social dimensions" of one's life"—which in plain language means that spirituality gives us the ability to rise out of our daily and physical struggles (pp. 231-232). Furthermore, while spirituality expresses and addresses the need for meaning, to take it a step further, religion can be the formal method in which these needs can be met (Meyerstein, 2005, p. 209).

Does science support spirituality?

The research on spiritual practice in health care repeatedly concludes that not only spiritual practice but, more specifically, religious practice (Kaye & Raghavan, 2002, p. 232), can be a hugely mitigating factor, lessening the negative effects of caregiver strain on those helping the chronically ill (Ashcroft et al., 2026; Kaye & Raghavan, 2002; Uğur et al., 2024). Further, Kaye & Raghavan (2002) found "religion (an expression of the person's spiritual perspective) as a primary means of coping with the stress of illness and disability" (p. 232). Additionally, where previous studies have found emotional descriptions of anxiety, stress, and depression, the spiritual research has discovered that caregivers have found feelings of gratitude and hope (Kaye & Raghavan, 2002; Meyerstein, 2005; Uğur et al., 2024).

In one study, which analyzed the content of prayers written on a Prayer Tree in an ICU unit in Southern Alabama, researchers found recurring themes of "healing, faith, love, thankfulness, encouragement, grief, and prayer of acknowledgement" with the predominant expressions, including prayers of "healing by a higher power, faith, love and thankfulness" (Ashcraft, 2026, p. 547). These findings align with a predominantly Muslim study out of Turkey which also found themes of hope and gratitude, as well as coping and relief, connected to the belief in a higher power. Some of the sentiments observed in the study included statements such as, "God gives challenges to the servants He loves," and "because I'm devout, I can show patience to Allah's destiny and test…. Allah gives me patience in return…" (Uğur et al., 2024, p. 4-6). Further exemplifying this positive fortitude, was a patient who provided solace through spiritual belief, "Mom, you'll go to heaven by taking care of me. I'll be waiting for you on the other side. I'll take you to heaven" (Uğur et al., 2024, p. 4-6). To this, the author must take a moment to say, simply—beautiful.

In a study on a predominantly Jewish-run support group, including Jews, Christians, and Muslims alike (with other religions welcome), which used faith-based group discussion and prayer as its therapeutic method, there emerged improved mental-emotional states, such as newfound strength, catharsis, problem-solving, coping, meaning, hope, gratitude, and increased spiritual development (Meyerstein, 2005). Interestingly, increased spiritual development was also found in the Muslim study, where participants reported a deeper and increased practice of spiritual learning than before the illness, in both family members and patients (Uğur et al., 2024).

Does spiritual practice benefit everyone?

Researchers discovered that the power of spirituality not only positively affected caregivers but also the patients with the chronic or life-threatening illness, themselves. For instance, one participant from the Jewish support group began by feeling "enslaved" and said that "life was being organized by chemotherapy appointments and feeling bad at home." However, at the conclusion of the study, he not only reported a "greater sense of control and connection in his life," but also found the strength to increase hopefulness and encourage his fellow group members (Meyerstein, 2005, p. 219). Other participants concurred and used descriptors such as moving, inspiring, and comforting. They also reported increased perspective from others' suffering, while viewing examples of courage, and described "enhanced feeling of balance in their lives, living alongside illness" (Meyerstein, 2005, p. 220).

The spiritual tools used in the Meyerstein study helped to "increase patients' perceived locus of control" ..."helped to manage panic and anxiety, lessening the sense of helplessness in relation to the illness...and helped participants to feel 'less alone'...and more connected to each other, their tradition, and God" (Meyerstein, 2005, p. 220). These findings coincided with the Muslim-based study wherein the patients expressed gratitude and were thankful for what comes from "Allah." They found "solace and meaning in the belief that trials are part of a divine plan," which helps to demonstrate a positive relationship between faith, belief, and mental well-being (Uğur et al., 2024, p. 6).

A quick note on "Healing".

It is important to recognize that through this spiritual lens, "healing" can mean many things, not just a cure. In Hebrew, "wishing someone a 'refuah shelaymah' (full recovery) implies healing of the body as well as the spirit" (Meyerstein, 2005, p. 208). As such, the desire and attainment of healing can extend beyond a cure. It can also apply to those who find physical or spiritual growth. Healing then becomes an ascension beyond the situational experience, as "strengthened coping, reduced anxiety, repaired brokenness in self and in relationships, and increased personal agency" (Meyerstein, 2005, p. 210). As such, we can say that someone has found healing if they experience improved functioning and appreciation of daily life, despite the continued struggle. In fact, Meyerstein proposed that "healing can also mean respecting a person's way of dying or 'healing unto death'" (2005, p. 210).

Can non-believers reap the benefits of spirituality?

Importantly, an intact belief system wasn't necessary to experience these benefits. In both the Uğur and Meyerstein studies, participants reported a larger increase of spiritual practice which had either been underdeveloped, dormant, or not experienced since childhood (Meyerstein, 2005; Uğur et al., 2024). Additionally, if one is returning to faith, it is it suggested to follow the counsel of how to proceed, as advised by the His Holiness the Dalai Lama, the spiritual and temporal leader of the Tibetan people. He explained that "there are many different religions and cultures in the world and each has developed to suit its own people. Because of that, I always recommend that it's best to keep the religion you were born into" (The Office of His Holiness The Dalai Lama, n.d., para. 1). He continues, "All religions offer help to humanity. Especially when facing difficult situations, all religions offer hope" (The Office of His Holiness The Dalai Lama, n.d., para. 5).

Final thoughts.

Jesus said, "For my yoke is easy, and my burden is light" (Matthew 11:30). How can this be true in times of trouble? As His words suggest, even in times of trial and illness, through spiritual practice, we can see the lightness and hope that can come from faith. In this, where some find anxiety and depression, others find gratitude and joy. In the book, Man's Search for Meaning (1946/2006), Holocaust survivor and psychoanalyst, Victor Frankl, echoes the powerful effects of being able to of

finding meaning in even the direst of human experiences. As such, is it is the hope of the author that if anything is taken away from this article, it is that—All is not lost. Regardless of your current circumstances, grief does not need to become the new norm. If one is brave enough, even the most skeptical and discerning of souls can embark on a beautiful and meaningful journey of hope, gratitude, and joy, through the pursuit and practice of faith.

Interested in pursuing a faith-based journey? Here's how to start.

1. **Consider prayer.**

   Prayer is simply talking to God or a higher power. It doesn't require complex words or rituals. One can pray anytime, anywhere, out loud, or silently. The most important part is being genuine and conversational, treating prayer as a way to connect with a trusted friend.

   Try out one of these Prayer methods:

   (a). Traditional and open-ended

   - Find a quiet space.
   - Address the divine (e.g., Dear God, Dear Allah, Heavenly Father).
   - Speak from the heart.
   - Close the prayer when done (e.g., Amen).

   (b). The ACTS method:

   - Adoration (e.g., Praise God).
   - Confession (Admit mistakes).
   - Thanksgiving (Express gratitude).
   - Supplication (Pray for your needs).

   (c). Pray, but also remember to listen. God speaks through your heart. As such, it is important to sit in silence, to listen and feel what God has to say to you. Also, monitor your daily life for the divine speaking to you, or answering your prayers in subtle ways—even if the response is not what you expected. You can also look for miraculous moments of beauty, which is God showing you his glory of creation. Remember, "God works in mysterious ways!"

2. **Find a local faith-based community (e.g., church, temple, mosque) that fits you!**

   Almost all faiths report the need and benefits of practicing in a faith community, rather than in isolation. The research also indicated important benefits from doing as much (Kaye & Raghavan, 2002). As discussed previously, a first-step recommendation is to stay with your original faith (The Office of His Holiness The Dalai Lama, n.d.); however, a change can also work if truly desired. Regardless, if interested in pursuing or renewing faith, one should connect with their local faith organization. It can be as simple as a quick internet search. Most faith-based communities and churches have their service times on their websites, as well as additional community activities

that they are hosting. You can even go on a quiet day, when no one is there, just to pray or walk the grounds. Finally, most faith-based members tend to be extremely welcoming. So don't be afraid to give it a try!

3. **Schedule an appointment with a faith leader.**

   Spiritual leaders, such as a priest, pastor, rabbi, or Imam can be a great source of help during difficult times. They are almost always happy to help and available to meet to have conversation on spiritual guidance and problem solving for a current situation. Contact your local faith center's front office to schedule an appointment. Additional fun fact—Their meetings are almost always free!

Additional Inspirational Readings from Sacred Texts:

New Testament and the Christian Perspective:

- "Blessed is the one who endures trials, because when he has stood the test he will receive the crown of life that God has promised to those who love him" (James 1:12).

Qur'an and the Muslim Perspective:

- "And We will surely test you with something of fear and hunger, a loss of wealth and lives, and fruits; but give good tidings to the patient, Who, when disaster strikes them, say, 'Indeed we belong to Allah, and indeed to Him we will return'" (Surah Al-Baqarah (2:155-156).
- "No kind of calamity occurs except by the permission of Allah. And whoever believes in Allah, He will guide his heart" (Surah At-Taghabun (64:12).

Old Testament and the Judeo-Christian Perspective:

- "When you pass through the waters, I will be with you; and when you pass through the rivers, they will not sweep over you. When you walk through the fire, you will not be burned; the flames will not set you ablaze" (Isaiah 43:2).
- "But those who wait on the Lord shall renew their strength; they shall mount up with wings like eagles, they shall run and not be weary, they shall walk and not faint" (Isaiah 40:31).
- "For You, O God, have tested us; You have refined us as silver is refined…We went through fire and through water; but You brought us out to rich fulfillment" (Psalm 66:10-12).

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Spiritual Care in Pediatric Hospice and Palliative Care

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Introduction

Pediatric hospice and palliative care goes far beyond pain and symptom management. Given this specialty is rooted in holistic, family-centered support, providers must deliver compassionate care that honors the beliefs, traditions, values, and sources of meaning that share how families experience suffering, hope, healing, and grief. Children who suffer from serious illness (and the families who care for them) often navigate profound emotional, spiritual, and cultural experiences throughout the course of illness, end-of-life, and bereavement— they should not do it alone.

What makes pediatric hospice and palliative care unique is the support not only to the patient, but also parents, siblings, grandparents, caregivers, and other family members who may be involved. Each family enters care with spiritual beliefs, cultural traditions, coping mechanisms, and lived experiences that are personal to them and, therefore, influences decision making, how they communicate, and what quality of life means to them. For these reasons, trained personnel who are experienced in pediatric development in relation to spiritual and cultural care are essential in providing compassionate, family-centered support during life's most difficult moments.

Spiritual Care

Defining spirituality has been described as nailing Jello to a tree. Spirituality is not an alternate expression to religion, but rather connects to religion as well as philosophy, ethics, existentialism, art, and nature. Spirituality attends to fundamental questions of transcendent awareness, relatedness,

meaning, purpose, and wholeness. In pediatric care especially, spiritual support often becomes entangled with hope, legacy, love, and the desire to maintain meaningful connection during complex situations.

For many people, their spiritual life is expressed and experienced within one of the world's religious traditions. Rather than expressing spirituality through organized religion, one may also express spirituality through individual practice, connection to art or nature. Spirituality may also be humanistic, centered on values of honesty, family, and hard work, or connected to work toward public causes. These are not mutually exclusive categories; many people include all the above and everything in between in their own spiritual life.

Spiritual care addresses the spiritual, religious, and existential dimensions of life. It is care that does not ignore physical and psychological processes but ultimately addresses the level of meaning. Chaplains and other spiritual caregivers assess the spiritual needs of patients and/or caregivers and develop a care plan to address those needs. They might coordinate with the patient's preferred faith leader, provide direct support, or both. Tools like non-anxious presence, reflective listening, and life review are appropriate for all interested patients and families to help them draw upon their own spiritual strengths and resources. Religious patients can also benefit from religious and spiritual practices like prayer, meditation, and rituals or devotional practices from their traditions. Most importantly, the chaplain holds a non-judgmental sacred space for the patient or caregiver to share and be heard, providing compassion and solidarity with one human being to another, even if the underlying circumstances can't be changed.

This model of spiritual care is an integral part of hospice history, philosophy, and practice. Dame Cicely Saunders, who started the modern hospice movement, would ask patients, "How are you within?" Her pioneering concept of "total pain" recognized that the pain and other symptoms associated with the dying process have physical/biological, emotional/psychosocial, and spiritual dimensions. These dimensions are present in every human person, and suffering in one area can and does impact the others. By the same token, addressing needs in one area can positively impact the pain in another. Spiritual care is one of the core disciplines of hospice alongside the physician, the nurse, and the social worker.

In addition to the chaplain being a vital part of the multidisciplinary team for patient and family support, in pediatric settings chaplain interventions with staff have been found to improve coping with workplace stress and result in greater work-life balance, collegiality, optimism, and initiative in solving problems.[2] This support can take the form of targeted interventions, informal check-ins, post death debriefing, or dedicated time at the hospice IDG meeting.

Fowler's Stages of Faith Development

One of the most influential models of spiritual development is James Fowler's Stages of Faith. Fowler was a theologian who based his study of human spiritual development on the psychological work of Jean Piaget, Erik Erikson, and others. Fowler proposed seven stages of faith development

characterized by how the individual approaches ultimate meaning, rather than the specific content of their belief or practice.[3]

Development through these stages happens in different ways for each person and is not routine. Children who have been through traumatic medical experiences may well be delayed in spiritual development just as they are in other areas. Similarly, their parents and caregivers may also be at an earlier stage of spiritual development due to the caregiving and high medical needs of the patient—or crisis may have created a drive to wrestle with spiritual questions all the more.

Stage	Fowler	Age in Years	Description
0	**Undifferentiated Faith**	0 – 2	"Undifferentiated" faith is characterized by an early learning of the safety of their environment (i.e., warm, safe, and secure vs. hurt, neglect, and abuse). Consistent nurture will develop a sense of trust and safety about the universe and the divine, while negative experiences can lead to distrust of the universe and the divine. Transition to the next stage begins with the integration of thought, language, and symbols.
1	**Intuitive-Projective**	2 – 7	"Intuitive-Projective" faith is characterized by fluidity of thought patterns. Religion is learned mainly through experiences, stories, images, and the people that one comes in contact with.
2	**Mythic-Literal**	7 – 12	"Mythic-Literal" faith (mostly in school children), is characterized by if a person has a strong belief in the justice and reciprocity of the universe, and their deities are almost always anthropomorphic. Metaphors and symbolic language are often misunderstood and are taken literally.
3	**Synthetic-Conventional**	12 - 21	"Synthetic-Conventional" faith, arising in adolescence, is characterized by conformity to authority and the religious development of a personal identity. Any conflicts with one's beliefs are ignored at this stage due to fear of threats posed by inconsistencies.

Stage	Fowler	Age in Years	Description
4	**Individuative-Reflective**	21 - 35	"Individuative-Reflective" faith is a stage of angst and struggle. The individual takes personal responsibility for their beliefs and feelings. As one reflects on one's own beliefs, there is an openness to a new complexity of faith, but this also heightens the awareness of conflicts in one's beliefs.
5	**Conjunctive**	35 - 45	"Conjunctive" faith acknowledges paradox and transcendence relating reality behind the symbols of inherited systems. The individual resolves conflicts from previous stages through a complex understanding of a multidimensional, interdependent "truth" that cannot be explained by any particular statement.
6	**Universalizing**	45 -	"Universalizing" faith. The individual would treat any person with compassion, as they view people as from a universal community, and should be treated with universal principles of love and justice.

Addressing the spiritual needs of children requires understanding what is developmentally appropriate. For the chaplain this means speaking honestly, even about difficult topics, but in concrete and age-appropriate language. A school-aged child may benefit from play and storytelling, whereas an adolescent hospice patient may well be ready for more complex conversations.

Support for adult caregivers means also assessing their spiritual needs and development. A chaplain must be ready to explore tough spiritual questions ("Where is God right now? Why do bad things happen to good people?") with those who are asking them but not impose those questions on those who aren't. This becomes more challenging when care recipients are at different stages and have different needs. The safe space that one person needs to explore what they really believe can be very threatening to another person whose certainty of belief is the only thing getting them through the day.

Research shows that caregivers of children admitted to pediatric hospitals who receive spiritual care experienced reduced religious/spiritual struggle and increased positive coping. Moreover, bereaved parents who receive spiritual support are more likely to find meaning in the loss, feel continued connection to their deceased child, and provide comfort for years beyond the death.

A Story of Spiritual Care and Companionship

One recent patient experience within our pediatric program beautifully demonstrated the profound impact spiritual care can have on children and families enrolled in a pediatric hospice and palliative care program.

December 2025, Pedi Full Life Care team under Empath Health cared for a medically complex child under our hospice program whose family wished for him to spend his final moments at home. Through extensive interdisciplinary collaboration and complex care coordination, our team was able to honor that wish and transition this child from the hospital to home for end-of-life care. The experience left a profound impact on not only the family, but also the pediatric team caring for the child and his loved ones.

Following the child's death, the chaplain who supported the family shared a heartfelt reflection stating the importance of the chaplain's role in caring for his colleagues as well as the patient and family caregivers. In his message, he thanked every individual involved in the Child's care—from those at the bedside to those behind the scenes, bringing it all together.

The chaplain reflected:

"I was a witness to incredibly skillful people providing not only compassionate medical care but empathy to everyone present."

His reflection emphasized something significant within pediatric spiritual care: empathy extends beyond the patient—it impacts parents, siblings, extended family members, and unique details within a family's environment that provide comfort and connection.

The chaplain noted that with traditional geriatric hospice care, the family may be grieving and reflecting on a long and complete life. Whereas the loss of a child is about potential and possibility of what could have been, adding a different dimension to the family's grief. The chaplain stated the child's parents were "early 20-somethings losing a kid, their firstborn. That's a whole other level of grief and loss."

One particularly meaningful portion of the child's story involved the family dog and the child's companion. Throughout the process, the dog remained near the child's bedside, quietly moving throughout the home and sitting next to family and members of the hospice team.

The chaplain warmly described the dog as the child's: "Spiritual support dog, perhaps."

Months after the child's death, the family continued to reflect on the dog's profound influence during the child's final days. During a bereavement follow-up conversation with our pediatric social worker, the child's mother tearfully shared that near the end of his life, the child unexpectedly said: "He is MY dog."

Shortly after the child's death, the family pup also passed away. Mom shared that she trusts the two are together now—a belief that continues to bring spiritual peace to the family during their grief journey.

Pediatric hospice specialists are welcomed into some of the most sacred and vulnerable moments in a family's life. Supporting children at end-of-life requires not only clinical expertise, but also emotional presence and empathy.

As the chaplain wrote about this case: "Empathy takes energy. And a remarkable amount was on display."

Stories like this remind us that spiritual care in pediatric hospice and palliative care is not separate from the medical portion; it is an essential piece of the puzzle that makes up family-centered care by addressing the whole person. Sometimes spiritual care is found in prayer or ritual. Other times, it is found in presence, listening, memory-making, compassion, or simply ensuring a child can be home surrounded by love.

In pediatric hospice and palliative care, hope is not removed but rather, it evolves. Hope may become peace, comfort, connection, dignity, or togetherness during the child's most difficult times or final chapter. Through spiritually supportive interdisciplinary care, pediatric hospice and palliative teams have the privilege of walking alongside families during moments of profound love, grief, and meaning— guaranteeing that no child or family walks their journey alone.

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Chaplains, Children, and Families

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It was the middle of an afternoon seminar on bereavement when my pager vibrated. I left the room to call the office and was directed to All Children's Hospital. A couple I knew well, Ted and Meredith, had asked for me. They were founding members of my last church, and being called to the children's hospital filled me with a sense of foreboding. My thoughts immediately went to their two children, Austin and Olivia, whom I had known since birth.

As I walked down the hall to the room where Ted and Meredith waited, I realized I was in a state of transition. For eighteen years, I had served as a pastor; now, I was beginning my ministry as a chaplain. These parents acted as a bridge between those two worlds. They had been founding members of the final church of my parish ministry, yet now they were calling upon me in my new role as a chaplain. While these two worlds shared many similarities, they were also quite distinct.

My previous churches were small, but they were not immune to the heartbreak and suffering of parents and children. I served at Believers Chapel in Birmingham, Alabama, for seven years, from 1976 to 1983. My wife, Patty, and I particularly remember the spring of 1980.

The events of that season began in August 1979, when a premature baby was born to an African-American couple in our congregation. The church rallied around them like family. After months in the Neonatal ICU, the baby finally came home, only to die suddenly a few weeks later in February 1980. It was devastating for both the family and the church, and I found myself in the middle of the grieving process on several levels.

The tragedies continued throughout that spring. On a Saturday morning in March, I was summoned to the hospital for another couple whose baby was born with Spina Bifida. Again, I was involved in a traumatic event, acting on instinct rather than formal training. My gut told me to avoid trite religious platitudes.

The following month, another couple in the church had their first child, a boy. Four days later, he was diagnosed with a hole in his heart; surgery was unsuccessful, and he passed away. It was my second infant burial in two months. May brought the death of a young woman in her mid-twenties—the daughter of a widow in the church—and another baby born with hydrocephalus. Finally, in June, my own father died of cancer at age 65. I had to navigate my own grief while consoling my mother and arranging his funeral.

The stress of that spring was never repeated, but it shaped my perspective on death and families. During those years, my primary focus was simply surviving as a pastor. Eventually, the demands of meeting the standards of elder boards took their toll, and after eighteen years, I decided I could take no more. I left with no clear idea of what lay ahead.

Within a year, I enrolled in Clinical Pastoral Education (CPE) at Tampa General Hospital, beginning a journey of self-discovery. My colleagues helped me define the things that had previously come to me only by instinct. I learned phrases like “making friends with your helplessness” and “stop talking and let the patients educate you.” CPE felt like taking off an old, ill-fitting suit of clothes and finally getting comfortable in a new one. It just felt right.

When I entered the hospital room to see Ted and Meredith, I was there as a chaplain, not their pastor. Ted, stoic as ever, stood to shake my hand, while Meredith sat on the bed with tearful eyes. I sat with them and asked them to tell me their story.

I learned that eleven-year-old Austin had been diagnosed with an astrocytoma, a tumor that could be treated but not surgically removed. I had no words to make it better; I remained sympathetic but silent. We prayed and parted for the time being. My CPE training had given me a facetious but accurate motto: “Shut up and do nothing”. As humans, we have an innate desire to fix people, but we are not mechanics—that is not our job. Our role is to enter into the pain of others and simply hurt with them.

By 1996, I was working for Hospice during the week and on-call at All Children’s Hospital on weekends. On my first day, a colleague, Chaplain Dave, introduced me to the Medical Intensive Care Unit (MICU). He told me about a near-drowning case involving a toddler who was brain dead. The child was to be removed from the ventilator and placed in his mother’s arms to die. Our role was to be there for the family and the staff.

I was continually learning the importance of “being there.” Sometimes it meant waiting silently for a peaceful end; other times, it meant staying in a “quiet room” where tears flowed. Families were grateful for a human being who would endure the pain with them and not run away.

I also received a lesson in cultural diversity while on call at Tampa General. A 16-year-old girl with heart disease was in the Pediatric ICU, awaiting a transplant. She had coded twice that night, and the damage was so severe that the staff would not resuscitate her again. In the waiting room, I heard the family’s intense wailing—a combination of moans and prayers begging God to keep her heart going. I worried about how they would react if she died.

Sometime after midnight, her heart stopped. When I entered the room, the family was calm. They asked me to give her a blessing, then quietly gathered their belongings, said goodbye, and thanked the staff. The expected “meltdown” never occurred. This experience taught me that different cultures express grief in vastly different ways.

Ministry roles are not interchangeable. Finding where we “fit” is essential, and it took years for me to find my place as a chaplain. However, the lessons I learned during my years as a pastor proved invaluable.

Austin fought a courageous two-year battle with chemotherapy and radiation. He reached the final scan that should have given him the “all clear,” but new growth was discovered. This time, Austin called for a stop; he could not go through the treatment again.

A few months later, I was called to the ICU at All Children's Hospital. Austin was on life support, and the decision had been made to make him an organ donor. A pastor led the room in a word of encouragement and blessing, and we were then dismissed as the process began.

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From Lives Remembered to Lives Interrupted: The Sacred Transition from Adult to Pediatric Hospice Chaplaincy

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Being a hospice chaplain usually means sharing those last moments with people, offering comfort, just being there as they approach the end of their lives. When you work with adults, the experience often feels like bringing a story to a close. These patients have had time to build families, gather stories, collect regrets, and sometimes find a bit of closure or forgiveness before they go.

However, pediatric hospice is a whole different universe. Suddenly, there's no neat sense of an ending. It's unsettling and honestly, pretty heartbreaking; it flips everything you thought you knew upside down.

This article takes a closer look at what happens when chaplains move from caring for adults to working with children in hospice. It's not just about picking up new techniques or dealing with trickier cases. It pushes chaplains to rethink everything: what suffering means, where to look for hope, how to spot something sacred in the middle of so much pain. They're forced to adapt, to find new ways to help families and young patients who are facing losses that just don't fit the usual mold.

A Personal Threshold: Encountering Pediatric Loss

I didn't see it as my calling when I was first invited to go into pediatric palliative care. I have come to find my calling in parish ministry and advocacy, as well as being rooted in the way of life within the church community, as I was formed at Virginia Theological Seminary. Although I started working in palliative care, I thought my call would stay with the adults, accompanying them as they neared the end of a long life.

However, ministering to children and their families in a pediatric hospice, requires a very specialized set of skills and a very different approach to pastoral care than I was prepared for at that time. I remember telling my wife that I may eventually be working in a pediatric hospice setting and she paused and replied with total honesty: "Please don't tell me anything. I know it matters to you, but I don't think I could bear it."

She was right.

There are moments in ministry that do not simply inform us, they alter us. Pediatric hospice became one of those thresholds.

The call came in the middle of my shift. A four-month-old child. The Treasure Coast Hospice administrator's voice was steady, practiced. The words themselves were not.

By the time I reached the hospital, the hallway outside the room had settled into that particular quiet that follows a death, soft footsteps, lowered voices, doors closing with care.

Inside, the air felt different.

The mother dropped to her knees beside the bed, leaning over him. Her hands trembled as they traced the outline of her child's face, slowly, deliberately, as though committing each feature to memory.

The father knelt beside her. One hand gripped the edge of the bed; the other pressed hard against his mouth, straining to contain what could not be contained.

A sound escaped him, raw, unformed, then broke into sobs that filled the room, pressing outward, leaving no space untouched.

My vision blurred. I lowered my gaze, blinking, but the tears would not hold.

The child lay still. Too still. Wrapped carefully, as though sleep might still be possible if handled gently enough.

Family members gathered in fragments, arms around shoulders, whispers that could not settle, prayers begun and abandoned mid-sentence. Grief moved through the room like a tide, rising, breaking, returning again.

I stepped closer.

No words came. None that felt equal to the moment. So I remained. I lowered my head. I placed a hand, gently, where it was welcomed. We breathed the same air, heavy, sacred.

Minutes passed. Or longer. Time loosened its grip.

Gradually, the room grew quieter, not because the grief had diminished, but because it had deepened into something shared.

And there, in that stillness, without explanation, without answers, prayer was already unfolding.

From Completion to Interruption

I never learned how to face this truth until that moment hit me. In adult hospice care, there's this

sense that everything is supposed to come full circle. Chaplains help people tie up loose ends, repair relationships, ask for forgiveness, and look back at a life with some kind of meaning. It fits right in with those scriptural ideas about finishing well. “I have fought the good fight, I have finished the race,” like it says in 2 Timothy 4:7.

That whole story makes death feel complete, even though it’s always hard. There’s a sense of closure.

But pediatric hospice just shatters all that. It doesn’t let life play out to a natural ending. It stops everything, too soon, too suddenly. Chaplains walk alongside families who aren’t just losing their child; they’re losing every hope and dream tied to that child. Birthdays that will never happen. Milestones that will never come. Stories stuck at the start.

You can’t fix this by just rewording things. The whole way of thinking about care has to change. The chaplain has to leave behind that idea of completion and step into a world where the pain won’t wrap itself up neatly. Meaning gets hard to find. Sometimes, all you can really offer is your presence, just being there, without answers or easy resolutions.

The Theology of Mystery and Lament

Chaplains are drawn further into the biblical tradition of lament and unresolved suffering in pediatric hospice. Scripture uses words to honor suffering rather than to explain it:

- “My God, my God, why have you forsaken me?” (Psalm 22)
- “Jesus wept.” (John 11:35)
- The story of Job and the innocent people’s suffering

These writings elevate suffering rather than alleviate it. They give protest, grief, and the silence that follows loss a voice.

Chaplains are urged by this theological change to give up trying to explain suffering. Rather, they are expected to represent a theology of presence within mystery, supporting families without trying to find solutions to unsolvable problems.

Incarnation and the Presence of God

The focus of The Incarnation now changes how people think of God. God is not seen as a distant God (or one who has no relation to suffering) but rather as someone who is a part of those sufferings.

Therefore, the way in which we think of Christ changes very dramatically:

- Instead of thinking of Him solely as the Good Shepherd that leads one back to God; we also are able to think of Him as someone who suffers completely in many of the same ways that we do.

This change in the way we see Christ affects the way we provide spiritual support to those who are

grieving and/or those who have lost their loved one(s). The primary offering of hope that we provide to those who are grieving is not the Gospel message (though that is important); rather, it is simply being there with them or with their loved one during their time of grief. The assurance that "I will be with you always," as the Scriptures indicate, implies the assurance that God "is," not as a distant God "that is," but one "who is in your sufferings."

Silence as Pastoral Practice

The role of language is redefined through the lens of spiritual care within pediatric hospice.

In adult hospice, structure such as prayer, life review, and sacraments are usually present. In pediatric hospice, however, a much more tolerant, attentive way of being is necessary. Silence takes on new meaning; it is more than the absence of sound; it expresses a different level of the spiritual presence. As Paul says; "The Spirit… intercedes with sighs too deep for words" (Romans 8:26).

Within this sacred silence, chaplains begin to understand:

- not all suffering requires an interpretation.
- silence can represent an affirmation of community.
- presence may, in fact, be the most genuine demonstration of faith.

Family-Centered Spiritual Care

Pediatric hospice care focuses on treating not only the child but the whole family. No longer is the care of the dying individual a priority like it often is for adult hospice patients.

Family members struggle with issues such as:

- Guilt, doubt, and uncertainty.
- Anger and spiritual confusion.
- Anticipatory and existential grief.

Siblings also struggle with confusion and fear, and may not have the words to communicate how they feel.

Therefore, the chaplain's role is to assist in:

- Creating opportunities for the family to express their grief.
- Supporting their relationships, particularly those that are frail.
- Helping the family to remember and honor their child with dignity.

Spiritual care in pediatric hospice is thus characteristically relational in nature, taking into consideration the shared, interconnected aspects of suffering.

Reimagining Hope

Although hope does not vanish from pediatric hospice; it takes on a different form. Hope no longer hinges upon a cure or resolution and comes forth in much more quiet, delicate ways including:

- connecting with others
- alleviating pain and suffering
- creating meaningful memories
- creating a continued expression of love.

The words of Christ provide a theological foundation for this: “Let the little children come to me… for it is to such as these that the kingdom of heaven belongs” (Matthew 19:14;). This is not sentimental comfort; instead, it is a declaration that the children belong. In this framework, there is no denying the existence of grief; instead, there is hope beside the existence of grief.

The Chaplain’s Transformation

Moving from adult hospice to pediatric hospice changes the internal structure of the chaplain. From certainty to humility. Linguistic complexity will decrease, but truth level will increase. Faith will shift from having an intellectual or logical understanding to an emotional connection with patients and families.

In this transformation, chaplains encounter God differently:

- not as one who resolves suffering,
- but as Emmanuel—present within it.

Conclusion

There exists an incredible theological mystery in pediatric hospice chaplaincy, the fact that life is delicate and holy. The chaplain’s responsibility is to respect the tension between these two realities without trying to find resolution for them and remain in that realm with families who are grieving.

If adult hospice proclaims, “You are coming home,” pediatric hospice bears witness to a different, yet equally sacred truth: “You are not alone—not now, not ever.”

About the Author

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Never Alone: The Role of Spiritual Support in Pediatric Care

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Several years ago, my wife and I were in the middle of the ocean on a cruise when we discovered that our kids were experiencing a medical crisis 2,500 miles away. Everything immediately turned to a haze. We became physically sick. It was disoriented. Unable to intervene, we were forced to depend on our families, the medical community, and our spiritual community. I'll never forget walking into a dinner hall with everyone laughing and singing "Sweet Caroline" while our world seemed to stand still.

When a child faces a serious medical diagnosis or crisis, families often describe it as a disorienting experience. Nothing hurts more than watching your kids hurt. It can take a long time to recover from the mental fog these experiences create. Life that once felt predictable suddenly feels unstable. Everyone else's lives seem to be moving forward at a normal pace while those requiring care experience the slow-motion, out-of-body experience of crisis.

Multiple times in the last year, I have personally walked into rooms where children were receiving care and their families were in crisis or despair. Though never easy, it is a privilege to be a stabilizing force in the midst of uncertainty.

In those moments, families are not only asking medical questions. They are asking meaning questions.

- Why is this happening?
- Where is God in this?
- Are we alone?

This is the space where spiritual support becomes critical.

Crisis Reveals Our Need

Medical crises strip away illusions of control. Parents who are typically confident decision-makers may feel overwhelmed. Care teams carry heavy emotional loads as they advocate and care for children in a vulnerable experience. Crisis reminds all of us of our humanity.

James 1:2–4 speaks of perseverance developing maturity through trials. In clinical language, this might be called post-traumatic growth. Spiritually, it is the strengthening of faith and character that only comes through adversity.

Crisis has a way of revealing both our weakness and our need for strength beyond ourselves. The psalmist writes, “The LORD is near to the brokenhearted” (Psalm 34:18). That promise resonates deeply in hospital rooms.

Spiritual community and care can enhance coping, increase resilience, and even offer meaning in the midst of suffering. When families engage spiritual practices and support from their spiritual community, anxiety can decrease and a sense of perseverance can increase.

In Christian community, spiritual support can reframe a crisis, offer the faith to see a miracle in the midst of a crisis, or be a catalyst for spiritual and personal growth after a crisis.

Spiritual Support Defined

Spiritual support in pediatric care must be clearly defined so it is not misunderstood. It is not proselytizing, pressuring families toward a particular belief system, or leveraging vulnerability for religious persuasion. It is not a replacement for medical expertise, nor is it a denial of clinical reality. Spiritual care does not minimize diagnoses, dismiss grief, or offer false certainty. Instead, it provides space for the formation of hope while anchoring people in the midst of uncertainty. It helps children and families interpret suffering without being defined by it.

For Christian families in particular, spiritual support may include offering hope in God’s promises—that He is near and able to redeem, restore, and bring wholeness—without resorting to spiritual platitudes that oversimplify pain. After all, the words “everything happens for a reason” are not actually found in the Bible. Authentic spiritual care respects the depth of suffering while gently pointing families toward the enduring hope we have in Christ.

The Necessity of Spiritual Care

Parents and caregivers needing or offering pediatric care carry both a visible and invisible weight. Medical fatigue is real due to the endless appointments, the complex terminology, the lack of respite, the interrupted sleep, and more. There is also decision exhaustion: weighing risks, consenting to procedures, and trying to absorb complex information while emotions run high.

This can create a quiet loneliness as families experience crisis or long-term care while internally wondering if anybody can relate to what they’re walking through. By reminding parents that they are not alone, that their weakness does not disqualify them, and that meaning can still be found in suffering, spiritual care helps stabilize these families and their homes. Even if hope does not guarantee a specific medical outcome, it does improve the ability of everyone involved to continue to endure while not losing heart.

This can mean:

- Greater clarity in medical decisions
- Reduced emotional reactivity
- Improved communication within families
- Sustained hope, even when outcomes are uncertain

Compassion Keeps You in the Room

Ultimately, Jesus is repeatedly described as a human who was moved by compassion. In one account, he sees a grieving widow and acts before she even asks for help (Luke 7:13). His compassion almost always preceded his intervention.

As an encouragement to those offering spiritual care to families in crisis or in pediatric care, your most powerful resource is compassion. It affirms that suffering is seen. It communicates dignity. It bridges divides. It is ultimately what must motivate us to action. It is humility and compassion that allows any caregiver to enter a family's sacred space without imposing.

Compassion makes our presence a support and not a burden.

Opportunities to Increase Support

Healthcare providers can incorporate opportunities for spiritual care in simple, respectful ways:

- Encourage families to reach out for spiritual care—encourage them to include their faith community in their crisis or journey.
- Normalize emotional and spiritual conversations as people process through crisis and disruption.
- Provide access to chaplaincy or community faith leaders.
- Support your peers in processing their own spiritual and emotional burdens.

Even small acknowledgments can significantly reduce feelings of isolation.

Never Alone

Even when God and hope feel hidden, many families discover, often in hindsight, that they were sustained in ways they did not initially understand.

In rooms filled with monitors and medical equipment, spiritual care quietly declares that a crisis does not have the final word. And in that truth, many find the courage to endure.

When my wife and I experienced our crisis, one of the first calls we received was from a pastor who showed up at the hospital in the middle of the night, held our kids, and called to let us know they were okay. The families I visited last year didn't all get to experience that same happy ending.

The good news? Hope is not dependent on our circumstances. Hope is anchored in faith. And spiritual care means offering that kind of hope to families in need...no matter the circumstance.

The Meaning and Ecstasy of Being a Pediatric Hospice Chaplain for Our Children and Families in Care with Capital Caring for Kids

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This paper is written with a very specific focus on the role of the pediatric hospice chaplain and the spiritual support provided to the families and children in service with Capital Caring for Kids (CCK). This is not an exhaustive study of theory and method, but more of a reflection on the opportunities provided and created by and for our families in service with CCK to interact with openness, vulnerability, and grace in relationships with the entire caring staff, of which the chaplain is a part. The framework of the paper comes from the CCK mission and vision statements guiding the care teams in service to the patients and families.

In the mission and vision of CCK, all clinicians and staff are guided by the following statements:

Mission: Provide Patients And Their Families With Advanced Illness Care Of The Highest Quality.
Vision: Be The Best Provider of Advanced Illness Care And The Best Place to Work In Healthcare.

The mission and the vision statements are guidelines for all clinicians and staff supporting the medically complex children and their families in service with CCK. In supporting our families, the CCK chaplain does not judge ideology or religious practice before acting to support our families. The chaplain and the CCK clinicians strive to become a coordinated team supporting our families with a plan of care focusing on the patient and caregivers' values, goals, and outcomes. This is a noninvasive process of learning and trust building for the CCK care team and the families.

The pediatric hospice chaplain has a unique position on the CCK care team. As the spiritual focus for the patients and the families, the chaplain is often designated as the religious person to initiate prayer, spiritual reflection, and application, as well as the officiant during religious ceremonies, such as memorial services. In this article, the methods the chaplain uses in the role as the religious person on the team reflects a process of co-discovering the sacred within our patients and families. In many ways this is a process of learned imagination, described by Jean-Paul Sartre as the intentionality of consciousness to think of what is not present.[1] For Sartre, and the author of this writing, human beings are religious creatures because they are imaginative; they are so constituted and intentional

in searching for hidden meaning in plain sight, and, in the process, achieve a peace that makes them, our patients, families, and the CCK team, truly alive, spiritually and emotionally, to each other.1

Numerous authors have written about the intentionality of consciousness. One author is Karen Armstrong who writes that there is a process of intentionality, regardless of circumstance, to live in the present with the infinite possibility of being happy.[2]

For many of the families of medically complex children in service with CCK, the intentionality of consciousness is found in the imaginative process of finding peace during the day; and once found, escaping into a world of ecstasy and imagination for a chance to be fully alive. For Sartre, this is the presence of nothingness.[3] In this state of nothingness, all things are possible for the families of our medically complex children. For some, there is the ability to form images that are not present to their senses through a process of imagining consciousness and thus creating an irreal world. For others, the experience of intentionality is a deep sense of peace and fulfillment in the moment through mindfulness and a sense of presence. In this world, reality is transcended, which creates freedom of intentionality for our families to discover a purpose within their choices and actions.[4] This irreal state of imagination can be used in their spiritual practices often through icons, like paintings and images, or a sacred object, that reinforces their spiritual practice of prayer.

The transcendent peace of being fully alive is overwhelming and quite moving as a process of enlightenment and imagination for our families. In this world of imagination, the foundation of freedom and intentionality form, which is the discipline of being fully engaged in the moment, often resulting in increased happiness and a settling sense of answered prayer as a core capability of perception.[5]

As Saint Augustine teaches, the presence given in prayer is the awareness of the unknowing, with a mindful awareness that, if you must understand it, it is not God. In the presence of prayer, there is a manifestation of our human wanting and need for a connection beyond our circumstances, understanding, and imagination. This connection is often in the form of a sign, as an answer to a prayer, or a settled direction that we are seeking in our lives. In the Torah, the sacred Scripture and teaching of the Hebrew Bible, perception and prayer in the current moment are described as Yishuv Hadaas; Yishuv, meaning settlement, and Hadaas, knowledge, or the present awareness of the settling and tranquility of the mind. This is a cultivated state of being in the now, which is essential for spiritual growth and prayer. In this cultivated state of presence, true inner joy and peace can be experienced by the believer. The theory and practice of Yishuv Hadaas emphasizes our experiences in the present, which gives the believer a sense of being, which is an active state of spiritual development. The practice of Yishuv Hadaas cultivates an enhanced state of mindfulness for the age-appropriate practitioner.[6]

For the families of pediatric hospice patients, the care plan is always in the present with an awareness of the patient's interconnecting relationships. This state of being for the patient is an age-appropriate awareness of distanceless presence. In this state of being, the patient transcends distance and time in the emotional connection with their loved ones and surroundings. This emotional connection brings the patient and families the inner peace and settling hope of a boundaryless world.[7]

The foundations of chaplain support for families and children in hospice services are described in this writing as age-appropriate psychosocial development, through trust and spiritual exploration. With explorative therapy and trust, the family members and children in service, ranging in age from 3 years old to 21 years old, engage in a safe space designed with the free expression of emotions and ideas that are unprogrammed; an imaginative space to express hopes, fears, trust, anger, uncertainty, and developing feelings affecting their psychosocial and spiritual well-being. In this exploring space, the chaplain is joined by the social worker to help the family members and the children discover their psychosocial-spiritual well-being by developing resilience, a sense of presence, and mindfulness, which can be an application of Yishuv Hadaas and scientific study.

In a 2023 NIH-HEALS study, with 200 patients, there was shown a positive correlation between the CD-Resilience Scale (CD-RISC-10) and the Mindful Attention Awareness Scale (MAAS). The NIH study concluded that there is a meaningful relationship between psychosocial-spiritual well-being, mindfulness, and resilience.[8]

Often, after these mindful pursuits of presence and well-being, there is a realization by the families that the peace they seek is not attainable nor can it be sustained in their present circumstances. As the chaplain on the care team, this reality of non-peace is often a breakthrough to the source of the patients' and the families' unrest.

In the unburdening of life, the poet, Katie Cooper, describes the unsuccessful pursuit of peace in her poem, "I Cannot Find Peace." For Cooper, the world is unconnected from our souls, with our minds racing with hundreds of thoughts, never at rest, never ceasing, tired of not knowing; a life evolving to question God's intent and the lost prospect of an attainable peace that will settle the reckless thoughts.[9]

The critical component for spiritual development and peace in Katie Cooper's world of turmoil and racing thoughts is learning to surrender control to what cannot be managed. In the loss of control, the families are presented with a sacred pause, a chance to just be, a time to let God be God, by surrendering to God's unfolding plan, which may not be in the CCK assessment, or the spiritual issues identified, or part of the spiritual interventions or goals in the patient's care plan identified by the chaplain. Why, then, is this surrender to God's perfect plan so important and yet, so difficult for our families to achieve? It's personal. As Katie Cooper asks in her poem, "I want to see, I desire to see, but why am I still so blind?

I cannot find peace-
It is nowhere in this world.
Silence does not exist, and
My soul is ever in turmoil.
My mind races with a hundred thoughts,
Never at rest, never ceasing.
There is no calm within me.

I am tired- Tired of not knowing, tired of wondering.
I am weary- Of this life and its emptiness.
Is Solitude a blessing or a curse?

Questions arise-of God, Life, Eternity,
But I receive no answers.
Has God given me the ability to think
Or to be tortured with things unanswered?

My soul is an ocean, turbulent and deep.
Under a sometimes tranquil surface
There are tides, pulling and pushing.
Back and forth, waves roll and crash-
Never ceasing, stirring up grains of sand Into a swirling haze.

It's so hard to see clearly at times-
All that is left to do is hope that peace will come, to settle the haze of reckless thought.

I want to see, I desire to see
But why am I still so blind?

For the pediatric hospice chaplain, an effective method available to help our families answer the nonclinical question, "Why am I so blind?" is prayer. A prayer of being fully present and engaged in life, a practice of Yishuv Hadaas, not a prayer of supplication or solicitation; not a spiritual regimen defined with ritual and abasement, but a prayer of surrender and the extreme response of laughter in communion with a loving God who knows what is best for us. This is a faith beyond all expectations and understanding. A faith of surrender. The type of faith that believes in God's mercy and the path of redemptive suffering to internal peace; the I Am of Scripture, who teaches what is best for you, a God who directs our way (Isaiah 48:17 (NIV). This is the type of prayer that Kahil Gibran describes as a communion with God, an embrace of peace and a settled presence as close as our next breath. A God who does not listen to our words.

The pediatric hospice chaplain must often help families and patients find hidden paths to their authentic heart when they are ready for prayer, often despite their hearts breaking with the emotions of worry, suffering, anger, anxiety, and fear. The prayer, outlined by Kahil Gibran, for our patients and families is to trust in what cannot be spoken, to pour forth their darkness into space, and surrender all supplication to the God within who wills what we will; in this holy communion, embrace what is not visible or spoken in sacred Scripture, until weeping becomes laughter in the holy communion of God's embrace. In this state of being present with God, the patient and the families' desires are God's desires. In this miracle of faith, our prayers become the desires of God for us, where words re not necessary and weeping becomes laughter. (John 16:20, Psalm 126:5), NIV).

For Kahil Gibran, this is agape love, a love that rejoices in the unconditional and sacrificial promise that "I am with you always, to the very end of the age" (Matthew 28:20, NIV), "know and believe the truth, and the truth will set you free" (John 8:31-32, ESV).

You pray *in your distress and in your need; would that you might pray also in the fullness of your joy and in your days of abundance.*

For what is prayer but the expansion of yourself into the living ether?

And if it is for your comfort to pour your darkness into space, it is also for your delight to pour forth the dawning of your heart.

And if you cannot but weep when your soul summons you to prayer, she should spur you again and yet again, though weeping, until you shall come laughing.

When you pray you rise to meet in the air those who are praying at that very hour, and whom save in prayer you may not meet.

Therefore, let your visit to that temple invisible be for naught but ecstasy and sweet communion. For if you should enter the temple for no other purpose than asking you shall not receive: And if you should enter into it to humble yourself you shall not be lifted:

Or even if you should enter into it to beg for the good of others you shall not be heard. It is enough that you enter the temple invisible.

I cannot teach you how to pray in words. God listens not to your words save when He Himself utters them through your lips.

And I cannot teach you the prayer of the seas and the forests and the mountains. But you who are born of the mountains and the forests and the seas can find their prayer in your heart,

And if you but listen in the stillness of the night you shall hear them saying in silence,

"Our God, who art our winged self, it is thy will in us that willeth.

It is thy desire in us that desireth. It is thy urge in us that would turn our nights, which are thine, into days which are thine also.

We cannot ask thee for aught, for thou knowest our needs before they are born in us: Thou art our need; and in giving us more of thyself thou givest us all."[10]

Conclusion and Closing Insights

For our families in service with CCK, God is unconditionally alive in the homes, the clinics, the hospital rooms, and in the hearts of all the children and parents calling out for a cure that may never come. Knowing that infinity rests in the moment when the pain and the worry subsides and a grateful mom, dad, or child senses the presence of Peace. In that sacred moment, the only response is "Thank you, Lord, for your faithfulness and love." For our families live beyond the sermons, the altars, and the prayers. They live where their God meets them on the hard road covered in the dusty soil.

"Leave this chanting and singing and telling of beads! Whom does thou worship in this lonely dark corner of a temple with doors all shut? Open thine eyes and see thy God is not before thee! He is where the tiller is tilling the hard ground and where the pathmaker is breaking stones .He is with them in sun and shower, and his garment is covered with dust. Put off thy holy mantel and even like him, come down on the dusty soil."[11] *Amen, Amen, and Amen*

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Bearing Witness: Pediatric Palliative Care in Amish and Mennonite Communities

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I received a phone call from the on-call physician: baby Samuel had died that afternoon. His death was not unexpected. He had been struggling with a respiratory illness related to his underlying genetic condition. The family had chosen to keep him comfortable at home with morphine, oxygen. and Ativan, supported by our home-based palliative care program. The timing of his death, however, was surprising. Just hours earlier, I had spoken with his mother, who shared that he seemed to be improving.

I went to the home the next morning. In Amish tradition the body of a loved one is returned to the home and remains there as family, friends, and church members gather to support one another. Funeral services are usually held in the home followed by burial with a horse-drawn hearse and buggy procession. When I arrived less than 24 hours after Samuel's death, I noticed the house was unusually quiet. Walking into the kitchen, I was greeted not by family, but by a baby goat crossing the floor toward me. A few teenage girls were cleaning and explained that the family had moved the gathering to a neighboring home to accommodate the expected crowd of over 300 people.

When I entered that home and stepped into the room where Samuel lay, what I witnessed will remain with me always. He was lying on a plain wooden church bench. His mother sat next to him gently dressing him and combing his hair. He was the 10th child in the family. His sisters and several other women stood closely around him, preparing his body for burial. Their heads were bowed in a quiet, reverent hush. Each garment he wore was sewn by the women and they shared softly that each of them had taken a turn at the sewing machine, contributing in a tangible way to this final act of care. Piece by piece, they tucked the simple white clothing around him with tenderness and intention. It was a moment where love, grief, and beauty were woven together in a way that felt both deeply human and profoundly sacred.

Experiences like this are not uncommon in my work with Amish and Mennonite families. They offer a powerful lens into how culture and faith shape the experience of illness, death, and caregiving within what are often referred to as the Plain Communities. I serve as a Registered Nurse and Program Manager of the Cherished Lives Palliative Care Program at the Clinic for Special Children in Lancaster County, Pennsylvania. The Clinic, founded in 1989, is dedicated to diagnosing and caring for children with genetic conditions, many of who come from Amish and Mennonite communities.

Located in the midst of farmland and rolling hills, the Clinic reflects the community it serves. Patients often arrive by horse and buggy as well as by car. While the Clinic is at the forefront of genetic research and diagnostic care, many of the conditions we see have no curative treatment. For some children, life expectancy can be measured by months or early childhood.

Because Old Order Amish and Old Order Mennonite individuals often generally marry within their communities, there is a higher prevalence of certain autosomal recessive genetic conditions. When both parents are carriers, there is a 25% chance with each pregnancy that a child will be affected (Puffenberger & Nolt, 2021). For many families, however, this risk does not deter them from having children. The value placed on family, faith, and community outweighs the uncertainty of medical outcomes.

It is not uncommon for families to experience the death of more than one child due to the same condition. Disorders such as Amish Lethal Microcephaly and a severe form of Nemaline Myopathy, TNNT1, can lead to death in infancy. These realities while heartbreaking, are integrated into a broader framework of belief that shapes how suffering and loss are understood.

The Plain Communities are rooted in Anabaptist traditions dating back to the 1500s. Emerging from a desire to live out faith separate from state control, these groups emphasized adult baptism, nonresistance, and a literal interpretation of the teachings of Jesus (Kraybill, Johnson-Weiner, & Nolt, 2013). Over time, distinct groups such as Amish and Mennonite were formed each with varying practices but with shared core values of humility, simplicity, and community. These values continue to shape daily life. Large families are common. Children are integrated into the functioning of the household from an early age. Community interdependence is not simply encouraged it is expected.

The nuclear family is very important and remains the bedrock upon which the Plain Communities scaffold their lives. They often have large families. Children are important but not the center of the household. They are included in making the family unit work by having lots of responsibilities in the household or farm. The community is rapidly growing because of their high birthrate and the Amish double in numbers every 20 years (Puffenberger & Nolt, 2021).

Their view on healthcare is influenced by their value for tradition and family. If it is something that has been used and done for generations then this is highly regarded. There is a natural hesitancy if something is promoted by ‘the world’ instead of ‘the church’. The world is anything outside of the church community or family. Transportation and cost of healthcare are also factors in what often appears to be a delay in accessing appropriate care. Many times families may not reach out for medical help until they have tried many home remedies and supplements. This can mean that their child is often quite sick before accessing traditional medicine.

For clinicians, working within this context requires a shift in perspective. Care is not delivered solely by the healthcare team—it is carried by the community. Decision making is often collective rather than individual. Interventions that prioritize comfort and presence may be more aligned with family values than aggressive, life-prolonging treatments. Trust is not built through expertise alone, but through humility, consistency, and respect.

In many ways, the goals of palliative care align naturally with the values of Plain communities: focus on comfort, the importance of family presence, and an acceptance of death as a part of life rather than something to be resisted at all costs. However, this alignment does not eliminate the need for thoughtful, culturally responsive care. It requires clinicians to listen carefully, to avoid assumptions, and to recognize that what defines “good care” may look different in each cultural context.

Being invited into these homes has been one of the most meaningful aspects of my work. These are spaces where profound grief and deep faith coexist. They are places where care is not rushed, where loss is shared, and where the community gathers not only to mourn but to carry one another's shared burdens. I often think back to the room where Samuel lay—the bowed heads, the white clothing, his mother's gentle work worn hands. It is a scene that represents how I understand both grief and care. In that space, I was not the expert. I was a witness. And in witnessing, I learned that sometimes the most meaningful care we can offer is not found in what we do, but in how we are willing to be present, quietly, respectfully, within a family's sacred way of loving and letting go.

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Spiritual Distress Manifested in a Teenager After a Stem Cell Transplant

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Abstract

A mother and nurse 20 years after her son's tragic death, after a high-risk stem cell transplant, learns that his major behavioral changes while in strict isolation came under the term of spiritual distress. Through her personal experience, the writer describes how her son's thoughts and feelings were expressed in behaviors, atypical for his usual demeanor. This article highlights the importance and value of healthcare providers listening to a parent's perceptions of their child's state of mind. Atypical behavior could be a manifestation of spiritual distress and requires further assessment from the health care team.

Key Words: Spiritual distress, pediatric spiritual pain, pediatric oncology, spiritual assessment, pediatric transplantation, pediatric end-of-life

They say that parents know their child best. I agree with this premise, especially when the child is seriously ill. The following story highlights how a parent's intuition should be taken seriously by health care professionals when it comes to a seriously ill child.

Our family was in a complicated situation when our 15-year-old son, David, was in strict isolation, after a high-risk stem cell transplant in 2000, at a prestigious children's cancer center. After being in remission for three and a half years, David's leukemia had returned and was more aggressive than before. We were unable to find a perfect match for a bone marrow transplant, and his only chance for survival was to receive allogeneic donor stem cells from his 10-year-old sister, Sarah, who was a near match. The procedure would be performed using a T-cell depletion, which ideally minimizes complications, especially from graft-versus-host disease. Before receiving the stem cells, our son's immune system had to be medically eradicated by total body irradiation to prepare him for the specialized procedure. Our daughter's donor stem cells were collected via apheresis, underwent treatment for the T-cell depletion, and were infused into our son. We then waited to see if the stem cells would regenerate and adjust to being in their new host. Sarah's transfused stem cells would become David's new immune system. He would remain in strict isolation until his platelet and other

critical blood counts emerged which took approximately 28 days. Anyone entering his room had to wash their hands meticulously, don a gown and gloves, and wear a cap and booties. Being quarantined like that had a profound effect on David's state of mind.

Around the second week after receiving his sister's stem cells, David's personality began to change. Our once easy-going, good-natured son soon started acting belligerently and was confrontational with the health care team. His change in behavior was unsettling, but the doctors and nurses assured us this was very normal for a child in strict isolation. My heart told me something different. I sensed he had concerns about his mortality and needed someone to talk to share his feelings. We called in a psychiatrist, but he could not decipher what was bothering David even after I told him my thoughts on the problem. None of the health care team members wanted to have this challenging conversation. Finally, in total desperation, I pleaded with David's favorite doctor to talk to him. The doctor appeared reluctant to have this dialogue, but we pressed on until he complied. We watch as he apprehensively entered David's room. Three hours later, he re-emerged. He appeared utterly exhausted and admitted to us that David had many philosophical questions about life. He then walked away like a defeated boxer. My husband and I then looked at each other apprehensively and wondered how David would behave after such an intense discussion. We entered his room, ready for whatever came our way. To our astonishment, David was sitting up in bed and displaying one of his magical smiles. It appeared as though a heavy burden had been lifted from his shoulders.

Seven months after having this existential conversation with the pediatric transplant physician, David died from complications from graft-versus-host disease, an Aspergillus infection, and multiorgan failure. The trauma of his death was so profound that we decided as a family to relocate to London to start a new life for our daughter, a new job for my husband, and for me to heal privately and on my own terms. There were just too many reminders of what we had been through if we stayed in our hometown.

My husband and I founded the Kanarek Family Foundation in 2006 as a way to pay tribute to David's memory and honor the man he could have become. The mission of the foundation is "to improve the quality of life for those affected by cancer and other serious, life-threatening conditions through the promotion, education, and integration of palliative and supportive care into all aspects of health care."

Our projects to date have included pediatric and young adult palliative care curriculum integration into Fairfield University School of Nursing (Fairfield, CT), financing the reorganization of their masters of nursing program to include stronger leadership components and establishing an advanced communication module for nurse practitioners caring for pediatric patients at Memorial Sloan Kettering Cancer Center in New York City by utilizing live actors for simulation. In 2017, the Kanarek Center for Palliative Care was established at the newly unveiled Egan School of Nursing at Fairfield University; the goal was to introduce all nursing students to the concepts of palliative care throughout their nursing education. There, they learn the fundamental components of palliative care, from birth to death, through didactic classes, clinical experience, simulation, and in-depth classroom discussion.

It was in this center, two years later in the spring of 2019, that I heard Christina Puchalski, MD, explain the role of spirituality in palliative care at a symposium at Fairfield University School of

Nursing. Dr. Puchalski was the keynote speaker—and I sat in the back of the room, eager to hear what she would say. She described her work developing an Interprofessional Spiritual Care Education Curriculum (ISPEC) for adult patients at George Washington Institute for Spirituality and Health with Betty Ferrell RN, PhD, from the City of Hope in Los Angeles.

Imagine, to my surprise, Dr. Puchalski began discussing the behavioral manifestations that adult patients demonstrated when experiencing spiritual distress. All the symptoms she described were those that David had displayed 20 years before when he was in strict isolation after his stem cell transplant! As she spoke, I had an epiphany—what I had guessed was David's fear of his mortality came under the term of spiritual distress. Finally, someone described an aspect of care that our son so desperately needed! At the end of Dr. Puchalski's presentation, I stood up and told everyone I had an "aha" moment and shared my story with them. Everyone in the room, including Dr. Puchalski, was aghast; we were sitting in the Center that had been established because of an unsettling memory of having no one willing to listen to a child's turmoil when they are so seriously ill. I had gone in a full circle in my healing, and it hit me like a bucket of ice water.

After that day, I spoke to a friend who also lost a child to a life-threatening illness. She acknowledged that she, too, had a similar experience with her five-year-old son before he died. The child sensed that something was wrong and became angry and inconsolable. My friend thought she had done something wrong. After I told her that her son might have experienced spiritual distress, she looked at me with a blank stare. It took several minutes for her to process the information. Then tears welled up in her eyes. She got it. Yes, her child had also gone through spiritual distress. The adult symptoms Dr. Puchalski described pertained to children as well.

I assumed David had questions about his mortality, but I now believe—a more precise term would have been that he was undergoing "spiritual distress." He had not received any emotional support or guidance from his health care team (and he was already aware of our distress and did not want to add to it) during this crucial time in his care and was suffering from lack of attentiveness to an essential part of who he was as a person. The U.S. National Consensus Project for Quality Palliative Care (4th edition, 2018) identified eight domains of care for those suffering from a serious illness; one of those domains includes spiritual, religious, and existential issues. Palliative care was not available when David was so ill; had it been, the palliative care team may have been able to elicit what was bothering David and intervene. Although I was most grateful to the physician who did finally have the conversation with him, I am still distraught that David had to suffer and that no one was willing to take the time to decipher what was the core of the problem. The health care team appeared more concerned with his medical progress and less with his emotional distress. It was evident that once David was able to share his feelings with an essential member of his health care team, his demeanor immediately improved.

A patient's mental and emotional state of mind is a crucial indicator of how one copes with a life-threatening illness. Palliative care, as we know it today, treats the whole patient and focuses on how to best address their concerns, how to improve their quality of life and assists in prioritizing what is most important to the patient and their family. As palliative care becomes more integrated into consideration for those who are seriously ill, it will be a foregone conclusion that rather than isolating

the individual both physically and emotionally, we follow the advice of Dame Cicely Saunders, the founder of the first modern Hospice. Saunders introduced the concepts of ‘‘total pain’’ in the 1960s, by addressing the physical, psychological, social, and existential/spiritual dimensions of distress. Anticipating that children have difficulty after transplant in strict isolation, the health care team could have initiated a discussion earlier, which would have prevented David from having to suffer needlessly and endure ‘‘spiritual distress.’’

It has been almost 20 years since David’s death. The conversation he had with his transplant doctor when he was in strict isolation after his stem cell transplant brings me solace in knowing that David had this vital conversation and felt better after doing so. Although our family continues to grieve his loss, I am forever grateful to the doctor who courageously took the time to help our son come to terms with what he was going through.

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Perspectives of Spiritual Care in Pediatric Palliative Care

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Spirituality, as defined by the National Consensus Project guidelines, is "a dynamic and intrinsic aspect of humanity through which a person seeks ultimate meaning, and experiences relationship to self, family, others, community, society, nature, and the significant or sacred."[1] Caring for the whole person includes assessment of physical, psychological, and spiritual needs. In pediatrics, another important consideration is the child's developmental age. The World Health Organization emphasizes that spiritual care is vital for enhancing quality of life and should be included in caring for patients and families/caregivers.[2]

The role of the palliative care team is to meet the patient/family/caregiver where they are and to listen with humble curiosity. They can then consider ways to offer support for the patient's unique journey and the impact it has on them as individuals. Leaning in and attentive listening are essential to building connections and developing a sense of trust. Providing a safe space to process is important.[3] "In order to provide effective care, pediatric spiritual caregivers need to engage patients on their level with love, curiosity and authenticity in a way that affirms them and what they are experiencing."[4]

"As spiritual carers of children in a clinical setting, embracing both the observable and explainable as well as the mysterious and ineffable, and the tension that sometimes appears to exist between the two, is tantamount to our being fully present with children."[5] The power of a ministry of presence can build rapport with the child. "After all, sometimes we can see the sacred, and sometimes we can only feel it, but either way, we know it's there in the midst of a shared experience."[6] Children learn, experience, and process through play. In your toolbox for spiritual care, consider the value and simplicity of play in building connections with pediatric patients at their level.

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.[2] Religious beliefs or nonbelief may affect care decisions. Be aware and respectful of the effect this may have on goals of care discussions/decisions and on end-of-life care. Respecting the beliefs and wishes of the patient/family is so important in the care we share as healthcare professionals. "Every family must be assessed and counseled individually for end-of-life decision making. Furthermore, every effort should be made to comply with parents' requests and to treat infants/parents of different, religions and cultures with utmost dignity so that they have no regret for their irreversible decisions."[7]

A pediatric patient/family/caregiver's spiritual or religious beliefs may offer a source of strength or coping. It may affect decisions for the plan of care and may be important aspects to review to honor their wishes and hopes with end-of-life care. "Hope can help create space for coping and healing, irrespective of whether the goal is cure or comfort and may change over time. Faith or spiritual beliefs may align with one's hopes."[8]

Including a spiritual care assessment is an important component of viewing the whole person. To do this well, all team members may prepare themselves as Spiritual Generalists. This allows us to capture important aspects of the patient's history. Beliefs or non-beliefs, as well as cultural considerations, can have a great impact on the plan of care we mutually develop to support what is most important to patients/families/caregivers. "For some health care professionals, spiritual care may be intuitive, but most will need to develop the knowledge and skills for providing high quality and competent spiritual care."[2] If indeed, a deeper dive in Spiritual Care is needed, we can count on our valuable Chaplains who are Board Certified and specially trained for this focus of care and ministry of presence.

Some educational resources to consider gaining this valuable knowledge in spiritual care may be obtained by participation in ISPEC-Interprofessional Spiritual Care Education Curriculum (ISPEC™). ISPEC© is an international, evidence-based curriculum for teaching all types of health care providers to address their patients' spiritual needs in a daily health care practice. This is an interdisciplinary course to provide care and recognition of the importance of spiritual care needs of individuals.[9]

Another resource, the Spiritual Care Association (SCA)- https://www.spiritualcareassociation.org/about/ is the first multidisciplinary, international professional membership association for spiritual care providers.[10] SCA offers online courses which bring insight to the spiritual domain and prepare care providers well to be more confident in including spiritual care assessment in the patient's history. This is available to all clinicians to provide spiritual support and assessment within the compassionate care they provide. They offer courses which provide a certificate as a spiritual care generalist.

Always lean on our Chaplains when specific spiritual needs or additional support are indicated. They are an invaluable part of the healthcare team and experts in Spiritual care. They can assist in facilitating the desires of family by meeting religious or cultural wishes to offer support.

PRAYER FOR GOD'S CHILDREN

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

Dear Heavenly Father,

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

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

God of love, ever caring, ever strong, stand by us in our times of need.

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

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

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

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

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

"Let the children come to me, and do not hinder them;

for to such belongs the kingdom of God." Luke 18:16

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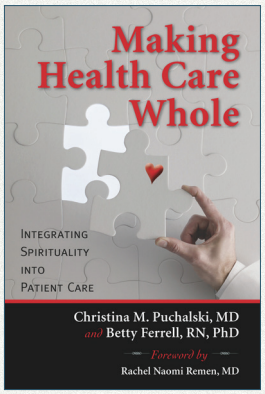
Readers' Corner



"Making Health Care Whole: Integrating Spirituality into Health Care" Reflections Through a Lens of Spirituality in Pediatric Palliative Care

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"Making Health Care Whole: Integrating Spirituality into Patient Care" by Christina M. Puchalski, MD, and Betty Ferrell, RN, PhD, is a very insightful book on the topic of spiritual care. It provides reflection and a deeper understanding of the need to incorporate spirituality as an intricate component of our assessment and plan of care in pediatric palliative care. "Spirituality helps give meaning to suffering and helps people find hope in the midst of despair." A national conference to discuss guidelines for incorporating spirituality into palliative care was attended by more than forty palliative care experts spiritual care experts. Their consensus findings form the basis of Making Health Care Whole.

"Making Health Care Whole: Integrating Spirituality into Patient Care" is a valuable and rich resource for the importance of assessment of spirituality for patients entrusted to our care. "Meeting patients and families where they are is essential to offering supportive care." Cecily Saunders, the founder of hospice and palliative care, speaks to the core of what spirituality means in the care of all patients. She coined the term "total care," and she understood the need to incorporate better overall care, not just for better pain control. Assessments should address spiritual, physical, emotional, and social dimensions, thus body, mind, and spirit.

Palliative clinicians seek to mitigate suffering in all forms. Pain can be physical, emotional, social, and spiritual. Therefore, spiritual care is an important aspect of total care. Puchalski states, "Spirituality speaks to what gives ultimate meaning and purpose to a person's life. It is that part of us that seeks healing and reconciliation with self or others." In pediatrics, this is an important aspect for the patient as well as the parents. We should not make assumptions but inquire about spiritual needs

and identify sources of strength and support. This helps to ensure that we honor Puchalski and Ferrell's view of spirituality as "inclusive of nonbelievers as well as the religious."

In Puchalski and Ferrell's words, "healing grows out of the clinical encounter between the patients and the clinician who expresses loving care, support and commitment to listen to all the patients' concerns, fears and beliefs." By looking at the whole person, body, mind, and soul, we gain a new perspective. This can impact the plan of care for this patient/family and how we may best support them.

One of the most impactful statements in this book for me reads: "The true practice of compassion does not lead to fatigue, as that compassionate practice is grounded in a spiritual practice." This puts the importance of spiritual growth in the forefront. The spiritual growth that takes place in each of us allows us to follow this call to serve, with a sense of peace, joy, and purpose. It is this type of self-care that sustains us to continue to serve those entrusted to our care. Eloquently stated in the book, "If compassion is practiced fully, and the health care professional has a spiritual practice to support that, there will be no fatigue, as the clinician is trained in a practice of compassion that includes healthy boundaries and self-care." Reading this statement was a moment of realization for me, preparing my heart to serve through daily prayer each day. Offering compassionate care for patients and families is a healthy coping strategy that fills me with great peace. Offering an authentic presence of supportive care, regardless of faith or non-belief, is imperative to extend our deepest respect for the dignity of everyone.

"For some healthcare professionals, spiritual care may be intuitive, but most will need to develop the knowledge and skills for providing high quality and competent spiritual care." As healthcare providers, we must develop the skills needed with training in spiritual care and compassionate presence. "Spiritual care also involves practicing the same values with colleagues as with patients." Treating team members with compassion, dignity, and respect. All team members may develop skills to serve them well in spiritual assessment.

"Excellent spiritual care can be thought of as a circular processing in which initial screening by clinicians leads to referrals to spiritual care providers who in turn conduct in-depth assessments and develop a plan of spiritual care, which is then shared with the team." Be sure to recognize the importance of including a Chaplain who is Board Certified as your spiritual care expert when assessment indicates this important referral. As the authors so eloquently state, "if you are not providing excellent spiritual care, you are not providing palliative care."

References:

Puchalski CM, Ferrell B. Making Health Care Whole: Integrating Spirituality into Health Care. New Age Books; 2010

Puchalski CM, Ferrell B. Making Health Care Whole: Integrating Spirituality into Health Care. Medicine and Spirituality Series, Motilal Banarsidass Publishing House; 2025

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.**

Events/Conferences

1. **Pediatric Palliative Care Webinar Series for 2027 will be announced soon!** There are still a few webinars left in 2026. Please find more information at www.ppcwebinars.org
2. **The Alliance for Care at Home Annual Meeting and Exposition** will be held October 27-30, 2026, in Washington DC – Registration and more information can be found HERE
3. **The Hospice and Palliative Care Nurses Association (HPNA)** is partnering with ELNEC to provide several upcoming courses. Information can be found HERE
4. **Alliance for Care at Home Advocacy Week** is September 13-16 in Washington DC; please save the date! More Information can be found HERE.
5. **HPNA** is also hosting HPNA on the Hill September 21-22, 2026. This includes a day of advocacy training in Washington DC. More information can be found HERE
6. Please save the date! The **Alliance for Care at Home Annual Meeting & Exposition** for 2027 will be held October 19-22 in Seattle, WA.

Additional Resources:

7. **The Funeral Services Foundation is offering two new resources!** Now, in addition to "When a Child Dies", there is a one-page companion piece, "When a Child's Death is Sudden". The second new resource is "When Goodbye Comes Too Soon", a guide for families navigating pregnancy and newborn loss. The resources are free; there is a small shipping cost. All resources are also open access and can be downloaded from the Funeral Services Foundation website. Click HERE for more information.
8. **Courageous Parents Network** has a whole new website! There is a wealth of resources for family members and providers. They are also offering free webinars and have a library of past webinars on their website. Click HERE for more information.

9. **Free music resource (music gift for patient/families) on behalf of Songs of Love…** Pediatric clinicians can offer Songs of Love as a joyful and uplifting gift for children facing medical or emotional challenges. By directing families to //songsoflove.org/request, they can request a completely free, personalized song written just for their child in any style or language, filled with the child's favorite things, people, and dreams. These songs bring smiles, laughter, and moments of pure happiness, helping children feel special, brave, and supported while giving families a lasting memory during a difficult journey.
10. **A wonderful resource that may be helpful is "Not if, but When),** a website that "encourages and supports sharing good books and stories about death and loss with children and teens throughout their lives." **Website:** www.notifbutwhen.org
11. **Academy Health: Enhancing Systems of Care for Children with Medical Complexity Newsletter** is a collaborative project with the University of San Francisco, Family Voices, Boston Children's Hospital, Patient Insight Institute, and Patient Advocate Foundation. More information can be found HERE.
12. **The Lucille Packard Foundation for Children's Health publishes the Children and Youth with Special Health Care Needs Network Newsletter –** includes news, policy updates, resources, events, and advocacy opportunities from across the nation. You can subscribe to the newsletter by clicking HERE.

Additional Opportunities:

Are there any Items of Interest you would like to share? Are there resources that you love? Please email Christy at Christy.Torkildson@gcu.edu

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