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Edited by Charles A. Corr, PhD, CT, Christy Torkildson, RN, PHN, MSN,
and Mary Kay Tyler, RN, MSN, CNP

Issue Topic: Spirituality and Pediatric Palliative Care

Welcome to the tenth issue of the ChiPPS electronic newsletter. The newsletter is produced by ChiPPS (the Children's Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO's newly-renamed Communications Work Group, co-chaired by Christy Torkildson and Mary Kay Tyler.

For this issue (and the one to follow) we are pleased to be able to offer articles on various aspects of spirituality from professionals who work in pediatric palliative care, as well as several contributions from parents who offer descriptions of and reflections on their unique experiences. We appreciate that everyone's experience is different. In this newsletter, we can only offer a sampling of personal perspectives from those parents who are willing to share their views with us. Nevertheless, we believe this sampling can provide food for thought, issues to think about, discuss, revisit with colleagues, and share with other patients and families. We welcome comments and suggestions about the contents of any of the issues of this newsletter.

Comments about the activities of ChiPPS, its Communications Work Group also are welcomed. We encourage readers to suggest topics, contributors, and specific ideas for future issues of this newsletter. Please contact Christy at ctorkildson@georgemark.org or Mary Kay at mktyler@hospicewr.org.

Issue #10: Spirituality and Pediatric Palliative Care
(Click on the "bookmark" tab on the left-hand side of the PDF document for links to the following articles.)

Struggles with God ***p. 3***
Lisa Buell
Lisa eloquently describes how she both struggled and found strength in her faith while living through the diagnosis, treatment, and death of her daughter Maddy. As she puts it, "My relationship with the Lord has always been a bit complicated" and now they "continue to be in conversation."

Pouring Salt on My Wound ***p. 6***
Lynda Cafasso (with photographs by Todd Hochberg)
Lynda shares her powerful story of losing her faith after her son was "born still." There are many lessons for us all in her difficult story, especially a reminder that words and actions can cause enormous and lasting pain.

When a Child Dies: Spiritual Struggles and Solace ***p. 8***
Beth Seyda, BS
Beth, as a bereaved mother and co-founder of Compassionate Passages, has experienced and worked with many families who have faced the loss of their children. Here she offers some families' perspectives, including her own, on soul-searching that may assist caregivers on how to better support bereaved families.

Are We Willing to Wait? **p. 13**
Randy Johnson, MDiv
Randy, using case examples, explores the issue of working with families who do not recognize or who deny their own spirituality and poses the evocative question, "Are we willing to wait and allow them to make their own discovery?"

The Importance of Meaning-Making: Where Spirituality and Grief Intersect ***p. 14***
Elizabeth A. Keene Reder, MA, CT
Elizabeth not only explores the importance of meaning making but gives practical and helpful suggestions to professionals that help answer the question, "How then can families best be supported around spiritual issues and meaning-making in the death of a child?"

Spiritual Care of Children with Life-Limiting Illness ***p. 18***
Paul Thayer, DMin
Paul provides guidance not only to spiritual care providers but to all members of the care team that helps us understand how to best assess and understand the spiritual concerns of children.

Pip and the Edge of Heaven: A Review ***p. 20***
Melissa Borth, RN, MSN
Melissa provides a short review of the book Pip and the Edge of Heaven, a potentially useful tool in working with children and their families.

Some Frameworks for Understanding Life and Death in Selected Examples of Children's Literature ***p. 21***
Charles A. Corr, PhD, CT
Chuck provides a wonderful selection of literature written for children that helps address the important subjects that often arise in discussions of religious, spiritual, or existential matters, and often concern the large-scale frameworks that individuals and groups use to understand and explain the relationship between life and death.

Items of Interest ***p. 24***
ChiPPS customarily shares items that may be of interest to our readers.

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STRUGGLES WITH GOD

Lisa Buell
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"Our family is more spiritual than religious," I would say to those concerned. I said it to many when our daughter was sick. Some understood, some were suspicious, all were very interested on our standing as if our affiliation would somehow determine our destination. Despite the queries, there never seemed words for the connection, or lack thereof with my "higher power."

My relationship with the Lord has always been a bit complicated. Sure it started out simple enough, I prayed for a bike and it later appeared, a mole like Ginger on Gilligan's Island and low and behold I woke up one morning and it was there! I prayed that I would be a scholarship athlete and it happened—a full volleyball scholarship. It almost seemed too easy, like God was the ATM of intention. Sure I would hear about tragedies: avalanches, hurricanes, mudslides that would kill or injure dozens maybe hundreds of people and I would chalk it up to "God's Plan" or on a more primitive level, "population control."

When I was in college, a young woman looking to have it all: husband, kids, coaching career, I thought I was a shoe-in, a sure thing. Imagine my surprise when after becoming engaged to the man of my dreams that I ended up being a lesbian! This didn't fit the idea of my perfect life, so I prayed… Sometimes I prayed from night until morning, a quick one between classes, another before practice and still I was a lesbian—talk about bitter. I felt as if I had been abandoned, the ATM was being serviced and I was out of cash. So I took a break, went it alone, determined to still have my dream even though it looked different than my original picture. Occasionally I would sneak in a prayer here or there, but for the most part the big guy and I weren't really speaking.

For some, becoming a parent is a choice, other's an accident, for me it had been a calling for as long as I can remember. Most of my peers were twelve and thirteen when they became "women." At fifteen, when I still hadn't, I prayed, begged, and pleaded, promising I would never complain of PMS, just as long as I could have babies.

After my daughter Madison was born I thanked Him for giving me such a wonderful gift, even though I knew she wasn't really "mine." From the moment she was born, after the doctor put her on my chest, skin to skin, I was in awe for all the obvious reasons, little feet, little hands, beautiful beyond belief. But there was something that struck the very core of my being, that her spirit was somehow richer than mine. That she was here to do something bigger than anything words could describe. I had no idea that our lives would change in just a weekend; that our perfectly healthy baby would wake up one morning with bruising around her bottom because she was trying to pass a tumor and we would be on our way to Stanford Children's Hospital.

During our first hour-and-a-half drive to the hospital, before the official diagnosis of cancer, we sang Maddy her favorite songs. I almost didn't want her to fall asleep for fear she would never wake up—it was the longest trip of my life. She did sleep, and during that time all I could do was hope, and pray and then the flood of guilt washed over me, The total knowing that God was punishing **me**, this was all happening because I was gay! How dare I think I could have it all! I was convinced of it, that is until I stepped onto the pediatric oncology ward and saw all the other sick children and their families and in that moment I knew God hated everyone equally.

I continued to pray because it was what I knew. I prayed because in times like these when life feels so arbitrary, you pull on whatever imaginary strings you can grab to make this puppet theater have a happy ending. I prayed because maybe it could make things right; if I framed my prayer differently, it would be answered. So I tried love, hate, indifference and still no answer. At the very least he should have taken me, and still nothing. During Maddy's illness and life, in the middle of the night, before every treatment, surgery, procedure, and test result my relationship with God continued to be complicated. A "healer" visited our home equipped with a seven-page prayer that we said over and over with him until it was memorized "Please Lord, thank you Lord, thank you Lord, thank you." Deals were made, family fences were mended, and still our daughter was sick. Positive thinking, visualizations, blending eastern and western medicines and still…

There were so many things we couldn't control, and at some point I switched my "prayers" to affirmations; "you're a strong and healthy girl," I would whisper in her ear as she nursed. I was present and grateful for every moment we had with our beautiful baby girl, who grew into an amazing, mesmerizing, charismatic toddler and I felt lucky to be one of her mothers. I was grateful for the love and support we got from our community, our family, and friends. It was during those times when I saw God, I saw God in the faces of all the people who loved Maddy, who would do anything for her, for our family. They gathered in our house, came to the hospital, knitted blankets, brought food, played games, sang, danced, and made our life so full. Madison was on several prayer chains, we did saging rituals, put crystals around the house, and I even drank horribly smelly concoctions that were supposed to go thru my breast milk to increase her immune system. My planter's warts vanished! And still…

God and I weren't really speaking at the time of my daughter's death and for many months after. Why talk to someone who doesn't answer, he didn't even have the courtesy to pick up the phone! There was no justification for such an atrocity, taking a child's life. I didn't have the energy to hate him; I just decided to not acknowledge his existence. The only thing I did have energy for was television and during my hours in front of it I couldn't help but notice how often athletes, actresses, and musicians would thank God for their victories, as if God somehow liked them more than the losers. Apparently He must have been too focused on the Super bowl to help our family. It was all very confusing; I tried hard not to get caught up in trying to make sense of any of it, because some things just don't.

I knew I couldn't live without her, I thought for sure that I would just wake up dead, or maybe that was what I was doing after all. Every day felt like I was walking waist deep in mud, the road was parallel to my course but all I could do was walk straight ahead thru the mud with the smooth open road just to my side, mocking me.

I envied the people who had a religion to identify with; something outside themselves. Even having their own book, and they were welcome in their churches all around the world. My house felt like it was falling down, that at any time I would implode around my feelings of loss and disappear into dust. They had a place to go, to be in their beliefs—ones that didn't have big chunks ripped out of them. Meanwhile, where did I belong? Not on earth where I no longer fit (a mother without a child), not in heaven with my daughter—if there really was such a place. Besides how would I get there? I wouldn't be let in if I killed myself, certainly if you die by your own hand you go to a different place, right?

My mind continued to spin, and again another day passed. Where did Maddy's spirit go? Her Spirit had been in and out of her body during the last days of her life, I knew when she was there and when she wasn't—how can I get to where she is now? All I could do was to keep her memory alive in my heart and the hearts of others. I could sit and be still, see her with my heart, conjure up her scent, and hold on to who I was before she left—because I really didn't like the person or whatever it was that I had become without her.

We made a conscious decision to have another child, more than one so they could have each other. My bond with my oldest brother became even stronger during Madison's illness and I couldn't imagine my children having to go thru this life without even the possibility of that kind of closeness. When I was pregnant with our second child I made a silent promise to myself that I would get up every morning, dressed and ready for the day. I would save my grieving for when the baby was sleeping, I was determined to keep my suffering from my child because it was my choice to have another baby. When our second daughter, Delaney, came I felt blessed again, but this time I said a quiet "thank you" to no one in particular. Delaney was born strong and healthy, (so had her sister so I continued to hold my breath). I became superstitious, overly protective, yet even through the fog of fear I intuitively understood that under the circumstances I had every right to be. I just didn't want to slip into crazy.

When Delaney got a fever for the first time at a year and a half, she spent the evening sleeping on my lap, and I spent the better part of the night in sheer terror—threatening, cursing this so called "God." My arms weren't too short to box with God, my threats piercing the night sky in search of my target. I swore at him for all the nights lost to fear, the fight or flight response to a simple sneeze, for the feeling of abandonment and for him taking my child instead of me. I tasted the metallic in my mouth, Delaney's hot hand felt like fire against mine, and the tears came. Is this who I wanted to be, angry, bitter, hostile? For what, some imaginary entity that continues to be unresponsive? Who am I hurting here besides myself? I sat there in the dark, transfixed on the rise and fall of my daughter's chest, and I too began to breathe.

If I hold anger I can't fully appreciate the beauty, I am not able to focus on wellness. In that moment, I did what I had done for years before in the darkest of times, I instinctively turned towards the light. The light within my own spirit, the glow of this beautiful little being that lay on my lap helping to open what I had walled up and protected for so long—my heart.

My jaw began to loosen as I remembered the friends who made multiple trips to the hospital bringing home cooked meals, take out Chinese, and gossip filled magazines. They brought presents for Maddy, spent their weekends and weeknights with our family, sometimes driving for hours in both directions so we wouldn't be alone. They held our gaze and our hands during the hardest of times and never let us fall. They contributed spiritually, physically, and financially to our family. "Tell me that's not God?" A voice came, born from my inner knowing; "Feel this baby you are holding and tell me… Remember the hardest and the best of times and you will see me there. I am the trees, the breeze, and the lightening. I am within the whisper and the yell. Hear my voice, see my face in the face of all that is and ever will be. I am in you, speaking as you. There is no separation, no space where I am not." I released myself to the voice; I released the fear, anger and sadness that held my throat tight. The tears fell, streaking my cheeks with their salty wetness. In that moment I realized that God wasn't something outside me, it is the energy that runs thru us all. That in fact We had been speaking all along; Madison, Delaney, my wife, our friends and family, the community that had embraced us—we were, are, and continue to be in conversation.

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Pouring Salt On My Wound

Lynda Cafasso
Mother of Joshua Cafasso Conroy born still January 12, 2006


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My church rejected my baby. Twelve hours after my son was born still on his due date I asked to see a Catholic priest because, as a life-long Catholic, I knew that babies had to be baptized and that you should ask for a priest to come when someone dies. When the priest entered the room it was clear he was uncomfortable and it seemed as if he didn't want to be there. He started talking about "God's will" and never looked me in the eye. When I asked him to baptize Joshua he said "Oh, is he here?" even though my son was lying in a crib right next to my bed. He then refused to baptize my son. My church, represented publicly and symbolically by this man, rejected my baby. He began lecturing to us about the three methods of baptism in the church: traditional baptism of a live baby, through martyrdom, and through "intention" when a baby dies inside the body of a Catholic mother who had intended to baptize him. So, he explained, "the baby" (never calling my son by name) was already baptized and it can't be done again. It really felt as if he was giving a class lecture and Stephen and I were his students. I was stunned. I couldn't believe that my church wouldn't accept my beautiful baby boy into the community of faith. Joshua was rejected. Unfortunately, because I wasn't thinking clearly I didn't yell at him and get him out of the room immediately. Instead, I politely asked him if he would at least say a prayer or bless Joshua or something! I so wanted and needed a religious rite performed for my son. The priest reluctantly moved so he was standing over Joshua and began to whisper something we couldn't hear, but it was clear that he didn't want to be doing that. It was only a few seconds long. Stephen immediately hurried the priest out of the room and I just cried and held my son telling him that I didn't reject him even though my church did.


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Because my church rejected my baby there was no way I could have a full funeral mass prior to the burial. I didn't even know if the church would agree to a mass and I didn't even ask. I simply was too hurt to want anything to do with Catholic tradition. In my mind, Joshua wasn't good enough for them simply because his umbilical cord kinked and he died. Because he died in an accident beyond his control he was rejected. I really felt as if I was protecting Joshua by refusing to allow the Catholic Church another opportunity to shun him. However, my family owned burial plots in a Catholic cemetery and there was a requirement that a priest or deacon preside over some sort of funeral rite. I agreed to a 15 minute prayer service at the cemetery and I requested that the prayer service be conducted by the wonderful, intelligent, fun Irish priest who presided at our wedding and had planned to perform Joshua's baptism. I felt forced into this by the cemetery rules and the need of my very Catholic parents to have a religious funeral for their grandson, but I was dreading it. However, I never could've predicted how damaging this would be and how the service would haunt me. The priest began the service by saying that no one knows "why God chose to take Joshua on his due date, but God did choose to do this and we must accept his decision". He went on to say that it was our duty to remain faithful to God and to continue to worship him. I thought: What did you say??? God did this? God intentionally took my beloved son from me before I even got a minute with him alive in my arms? You are saying God did this and I must accept it because God knows best?? I literally bit my tongue because I wanted to scream at the priest and run out of the chapel. I simply shook my head, buried my face in my husband's shoulder, looked at a picture of my Joshua and wept. I didn't hear another word the priest said. I was devastated and I felt my church had injured me twice during the worst time of my life. I asked for comfort and I received pain. I can't step into a Catholic church now. I can't refer to myself as Catholic. I wish I'd had no contact with any priest in the days following Joshua's death. It was hard enough to lose a child. Because of those priests I've also lost my faith.

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WHEN A CHILD DIES: SPIRITUAL STRUGGLES AND SOLACE

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It's not the wound that shapes our lives, it's the choice we make as adults between embracing our wounds or raging against them. ~ Geneen Roth

Introduction

One of the many challenges parents may face after their child dies is how this loss fits within their spiritual/religious beliefs. Families may not have had their faith tested before and this experience may force them to consider those big life and death questions.

This article offers some families' perspectives, including my own, on soul-searching that may assist caregivers in how to better support bereaved families. The terms "spiritual" and "God" are used here in a very broad sense and are not necessarily connected with organized religions/institutions.

Debra and LeRon

One of the stories from my award-winning educational film, *When a Child is Dying*, includes bereaved mom, Debra, talking about her son, LeRon, who died at age 10 from cancer. Throughout her story Debra shares the struggles with her spiritual/religious beliefs during the five years of LeRon's illness and after his death. Debra has a more traditional religious background, belongs to a faith community, and regularly attended church services. Debra describes how when LeRon was ill she hid her Bible, stopped praying, and was angry at Christ. Later she gave Him a piece of her mind and "just let it all out." After that she started reading the Psalms and a couple of them kept her going.

During particularly tough times Debra turned to friends who were more religious and they went to church together. She felt "the Lord had given me this wonderful child and there was not a time limit. I believed that the going out was just as important as the coming in. We had a wonderful pregnancy and now this was another test. I didn't know what or how to do it, but I felt like I would know how somewhere along the line."

Near the end of LeRon's life Debra's "religion was outside." She planted every inch of her mother's yard and didn't have to buy any vegetables for six months. Debra felt like God was teaching her that although He was taking her son, "there is still life, there is still something else and whatever it is you can do it with abundance."

After LeRon died, Debra held a celebration of his life with his favorite music and Disney songs. His purpose, as Debra looks back, "Was grand. He's left a lot behind and I'm still feeling the ripples of it as I go about. There's never a day that somebody doesn’t ask me about him or remember something."

Me and Dylan

It has been ten years since the death of my infant son, Dylan. I refer to my experience as a spiritual awakening. My husband and I were raised in religious homes (Jewish and Catholic, respectively), but neither of us has practiced any religion for 30+ years. We are exposing our six-year-old son, Tyler, to a variety of spiritual concepts and religious rituals so he can decide if/what he wants to believe.

I too was angry and Dylan's death forced me to ask many of those big questions. I primarily devoured books that I hoped would provide some insights. My heart felt like it had broken, so it was open and I wonder if that is why I seemed more receptive to new spiritual ideas. I did not agree with everything I read, but they made me consider possibilities I never imagined. For example, I had envisioned Heaven as a place where souls just hung out. But now I believe the universe is an active place full of angels, spirits, and guides that help us with our journeys here on earth. I had never given much thought to reincarnation, but now past lives could explain some things.

I would also see and hear things (e.g., on TV, in magazines) that resonated with me and helped put into words the shifting that was taking place inside. These include his "illness was a gift," "use your work to make a difference," and "maybe what happened today didn't happen *to* you, maybe it happened *for* you." Please see the list at the end of this article for the books I read on my initial spiritual quest.

Back when I was about six months pregnant with Dylan, one of my sisters called to see how I was and what was the latest update from the doctors (we had received a prenatal diagnosis of a congenital diaphragmatic hernia). I proceeded to tell her how much I was having to learn – be patient, no control, anatomy, medicine, etc. She very matter a factly responded, "Oh, Dylan is a wise, old soul, he's here to be a teacher."

"Why do you say that?" I asked. "Did you just listen to yourself, would you be learning any of this if it weren't for Dylan?" she asked. "No", I replied. I recalled that conversation months after Dylan died. I thought about how much more I learned during our pregnancy, Dylan's time with us, and since he died. Family and friends tell us what they have learned. Now when I think about what my sister said back then, I know she was right. Dylan was here to be a teacher.

I have signed up for the life-long journey on this, it's been a slow evolution, and I am not the same person I was 10 years ago. Dylan's birth and death taught me to be more present and pay attention to my life, I am a better mother, I am more compassionate, and I know that his spirit is always with me and guides me.

Asking "the BIG questions" and Spiritual Stages of Grief

Since the death of a child goes against what we believe about life -- that we will not outlive our children -- the automatic question is often WHY. Why did my child die? Why did my child/family have to suffer? Some parents might be able to verbalize these questions and feel comfortable engaging others in discussing them. Others may be quieter with internal dialogues, as it can be frightening not only to ask the questions, but then possibly to receive answers.

Some other common big questions are -- Are we being punished? (possible translation -- Did my child die because I did something bad?) Where is my child now? Did s/he go to Heaven? (possible translation -- Is there an afterlife? Is my child safe?) Will the pain ever go away? How can I go on? (possible translation -- What will my life be like now?) Do we want another child? (possible translation -- What if our next child dies?)

Whether members of a faith community or not, parents may be confronted with some of the following emotions about their spiritual beliefs:

Anger: Families may for the first time doubt and question long-held beliefs. They may turn away from God and not participate in their faith community. This is when they are often asking "Why?"

Working through the Anger: Parents may actively search for answers to their questions. They may do this within their church, they may seek other resources, or "try" other religions. Current faith communities can pose obstacles -- questioning faith might be viewed as sacrilegious/sinful and/or cause guilt. If not active in a faith community, parents may not know where to turn.

Reexamining Faith/Rethinking God: Parents may examine their previous beliefs, let them go, and create new ones. They may have strayed from their church and now return. This can be a time of great change and exploration of new ideas. This might be when someone may move from being purely religious to a broader, more spiritual view.

Parents often ask the big questions when they are experiencing many emotions. So while they may be asking, they are *not* ready for any answers. And then there are the people who just offer you their unsolicited opinion of God's plans. I love this quote from Amy Kuebelbeck's book, *Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life,* because this type of thing happens all the time. *"'You are so strong.' 'You are taking this so well.' 'I could never handle losing a child -- I don't know how you do it.'" These apparent compliments, given by well-meaning people to parents whose baby has died, are not particularly welcome. Perhaps the most puzzling platitude is 'God never gives you more than you can handle.' What's that supposed to mean? That weak parents get to keep their babies and strong ones don't? If that's the deal, I wish somebody had told me that going in.*

Debra's anger phase is clearly recognized, but then over time she became more reflective about LeRon's purpose and what this experience meant to her. She walked away from her religion and came back.

Parents Bob and Mary, had some spiritual differences after their premature twin, Gabriella, died. Bob found it helpful to go in the church that was in the hospital and say a prayer every day for Gabriella. He didn't ever feel angry at God or betrayed by Him. Mary did question her religious beliefs and because she was questioning them wondered if her beliefs were not as strong as she had thought. Mary hasn't figured it out yet and she is trying to put it all together.

We had a lifetime of plans and dreams for Dylan. At first that was all we could think of, all the things that were never going to happen. I felt robbed. But as we replayed all the events, we freaked out because it was clear how close we were to losing Dylan twice in those first 24 hours. This helped change our perspective, we were so lucky to have 2 weeks with him. Those 2 weeks were a lifetime.

Lessons Learned

The death of a child can be a profound and transforming experience for families, a "new normal" emerges. Parents may slowly figure out how to integrate the love for and loss of their child into their lives. Families may be changed as a result -- different priorities, outlooks, and dreams for the future.

Her daughter's death made Mary realize that nothing is guaranteed in life and taught her how precious life is. Mary now tells the people she loves, she "loves them" every day, and lives her life that way.

Pat, mother of teenage son Jodie who died, looks at the world totally differently. She appreciates things "a hundred thousand times more, very simple things." Pat knows that being here is all about love and Jodie taught her that -- how to accept love and how to give love.

My experience has me feeling very vulnerable, but not the kind where I am afraid to do anything because something bad may happen. Because our sweet, innocent Dylan died, I know now we are not special and protected from tragedy. We never know when someone we love will be taken away, so I want to take advantage of all opportunities to live, learn, and love.

From talking with bereaved parents, reading stories, and collecting eulogies, here are some common themes and spiritual lessons learned:

- Love never dies
- Be present, in the moment
    - Pay attention to life
    - Live life passionately (don't just go through the motions)
- Compassion
    - Better understand pain and suffering
- Gratitude
    - Appreciate small things
    - Focus on what have vs. not have
- Inspired by child's courage
    - Examine own fears
- Focus on what's really important (don't sweat the small stuff)
- Balance head and heart
- Beauty of the circle of life
- Teach what you have learned
    - Live by example

Supporting Families
Caregivers can support families in various ways:

- Acknowledge it's normal to question spiritual/religious beliefs
    - Struggles can occur any/multiple times -- at diagnosis, during illness, after death
- Journey with the family -- allow them to go through spiritual stages of grief
    - Uncertainty is challenging
    - Religion may/not provide comfort
    - Institutions may foster blame and guilt
    - Be wary of those offering "the answer"
    - Be open to wherever insights may come from that cause reflection and clarity
    - Stick with them as it can be a long and lonely journey
- Suggest discussing issues with a "spiritual care" counselor
    - Not necessarily a religious person/clergy
    - Needs to be open to/support the journey
    - Good listener
    - Try to uncover the *real* concerns behind the questions being asked
    - Offer options/resources

Spiritual journeys can take many paths and detours, there is not only one way. I was reminded of this when I spoke with a woman sitting next to me on an airplane. During our flight we learned we both were bereaved Moms and exchanged stories. Our religious/spiritual beliefs came up and we were polar opposites. She believed her daughter would remain dead until Jesus Christ arose. She looked at me like I was from Mars when I described some of my spiritual beliefs. But what struck me was that the end result was the same, we were both at peace.

Final Thoughts
It is difficult to accept that "good things" can come from the death of a child, but my wish is that all families and caregivers be open to the possibility of spiritual growth and receiving gifts from these children.

***Understanding:* What happens to you does not matter: what you become through those experiences is all that is significant. This is the true meaning of life.** ~ Zen Cards by Daniel Levin

Books that I Read while Seeking Answers to "The Big Questions"
A Grace Disguised: How the Soul Grows Through Loss by Gerald Sittser
Angelic Presence: Short Stories of Solace and Hope After the Loss of a Baby by Cathi Lammert and Sue Friedeck
Conversations with God (Books 1-3) by Neale Donald Walsch
Destiny of Souls by Michael Newton
Embraced by the Light by Betty J. Eadie
Empty Cradle, Broken Heart by Deborah Davis
Friendship with God by Neale Donald Walsch
Journey of Souls by Michael Newton
Synchronicity as Spiritual Guidance by Mark Thurston
The Celestine Prophecy by James Redfield
The Laws of Spirit: Simple, Powerful Truths for Making Life Work by Dan Millman
The Seat of the Soul by Gary Zukav
The Tenth Insight by James Redfield
Tuesdays with Morrie by Mitch Albom
Transcending Loss: Understanding the Lifelong Impact of Grief and How to Make it Meaningful by Ashley Prend
Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life by Amy Kuebelbek
When Bad Things Happen to Good People by Harold Kushner
Writing to Heal the Soul: Transforming Grief and Loss Through Writing by Susan Zimmermann

Other Books with Spiritual/Religious Themes
A Grief Observed by C.S. Lewis
Lament for a Son by Nicholas Wolterstorff
Psalms of Lament by Ann Weems
The Spiritual Lives of Bereaved Parents by Dennis Klass
When a Child Dies by Carol Pregent

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ARE WE WILLING TO WAIT?

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Spirituality is, of course, a part of the human experience for each of us; however, knowing or exploring our spirituality is not always part of the human experience. As spiritual caregivers when we encounter a patient or family with a seeming spiritual void we fight the urge to plant our own spiritual framework. Observing their apparent lack of spiritual underpinnings is painful. It is equally painful to wait for the patient or family to experience an epiphany.

We are all spiritual beings and for some this aspect of ourselves is explored all through life. It is fostered by families, faith communities, et al. I believe that spirituality is latent in all humans – the question is, Are we willing to wait and allow them to make their own discovery? If we are willing to wait we may very well witness the birth of one's spiritual awareness.

A case in point is that of Mark and his family. Mark was a 17-year-old Duchene's Muscular Dystrophy (DMD) patient with three siblings and two parents whose story offers us insight into spiritual care and discovery. The nuclear family had neither a history of involvement with any faith community, nor any inherited spiritual constructs. The chaplain's attempts to explore spiritual history or concepts with patient and family were constantly presented with dead ends. One attempt was with the use of markers and poster board. The chaplain asked if they could draw a picture of God or something related to God. No! They looked at the poster board and could not think of any way that they could conceptualize the divine. Neither nature trips nor religious holidays ever offered a window of opportunity to further explore their spirituality. It was difficult, but the choice was made to build relationships and wait for the patient and family to discover their own spirituality.

Nearly four years of regular visits (every 3-4 weeks) passed before that window of opportunity presented itself. It was the day before the patient died that he shared a vivid dream. Two nights before, his uncle (who had died from DMD nearly ten years prior) came to him in a dream walking and very happy. He said he was coming soon to take him to heaven. He would be able to walk and run and everything would be alright. The dream had not alarmed the patient or family, but brought comfort. In fact the patient told his mother not to worry about him; everything was going to be alright. This dream, a spiritual epiphany, opened the door for establishing a spiritual framework for the family that brought comfort.

Another of the patient's siblings also suffered with DMD and ongoing support remained with the family for several years to follow. This allowed the chaplain an opportunity to continue to explore with the patient and family spirituality and its structure appropriate for their needs all based on their own discovery. There were many healthy conversations about where Mark was now and where we would all go when we die. Prior to this time conversations about death or spirituality were met with resistance. Because the chaplain was willing to wait and allow this spiritually unaware patient and family to discover their own latent spirituality they are now able to better cope with death and loss and possess constructs for future development.

It may be difficult but sometimes the most important thing we can offer to others is our presence and a willingness to come alongside when our patients and families are ready. It means we must be vigilant in our listening and always ready respond to their cry.

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THE IMPORTANCE OF MEANING-MAKING: WHERE SPIRITUALITY AND GRIEF INTERSECT

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Research continues to show that the death of a child is one of life's most devastating events (Riley et al., 2007). One major factor in how people cope with grief is one's ability to find meaning (Neimeyer et al., 2006) and for many bereaved parents the issues surrounding meaning-making can be closely intertwined with spiritual issues. In the medical, nursing, and pastoral care literature, the definition of spirituality often includes some reference to how people find purpose or make meaning in their lives (Sulmasy, 2006). For some bereaved parents, their spiritual or religious beliefs are a source of comfort, while others question how God could take their child from them or allow their child to die.

Neimeyer proposes that the central task facing those who grieve is to "affirm or reconstruct a personal world of meaning that has been challenged by loss" (Neimeyer, 2001). Beliefs about how the world works (our assumptive world) may be challenged or affirmed at a time of loss. For parents this can be particularly difficult as the general assumption is that children do not die before their parent. Underlying these assumptions are values and beliefs that form our assumptions which in turn may lead to questions about the meaning of events or affirmation that our beliefs are upheld. (See examples in Table 1.)

Table 1 Examples of Beliefs and Assumptions Underlying Meaning-Making

BELIEF	ASSUMPTION	MEANING
Life is fair.	Usually people get what they deserve.	Why is this happening to us?
	If I live right, good things will happen.	What did we do to deserve this?
God is all-powerful.	God could choose to intervene and save my child.	Why didn't my child warrant a miracle?
	This must be part of God's plan.	I must trust in God's wisdom.
There is a natural order to life.	Children should not die before their parents.	I must not be a good parent.

There appear to be three aspects of meaning: making sense of the death, finding benefit, and reorganizing one's identity (Neimeyer, 2006). In trying to make sense of the death, the bereaved often turn to spiritual and religious beliefs. They may attribute the reason for the death of their child to God's will, randomness, or other beliefs from their assumptive world. They may focus on beliefs about the afterlife and draw comfort from the fact that their child is no longer suffering or in pain. Sense-making may also include assuming some personal responsibility for the death (Davis et al., 1998). In one study, those who made sense of the loss earlier in their grief process experienced less distress. And those with religious and spiritual beliefs prior to the death were more likely to be able to make sense of the loss (Davis et al., 1998).

However the element that seems to be most crucial is the ability to find some benefit after the loss. Examples of finding benefit could be personal growth, such as greater compassion, forgiveness, or tolerance; reprioritized goals; or improved interpersonal relationships (Riley et al., 2007). In one study about the death of an adult partner, those who found benefit experienced less distress and this correlation grew stronger as time went on, thereby affecting the bereaved person's adjustment more than the ability to make sense of the loss (Davis et al., 1998). For bereaved parents, the ability to find this type of meaning can be crucial but sometimes impossible. Bereaved families in our area have also worked on ways to honor the memory of their children: they have established centers of grief and loss to support other families; developed foundations to further research about their child's disease; created special comfort bags to provide practical items for other hospitalized families; and implemented a community toy drive and delivered the toys to the children's hospital on the child's birthday. Yet some of the parents have remarked, "I'd trade all that I've learned and all that I've become to have one more day with my child."

The third element, reorganizing one's identity, is especially relevant for parents. If an only child died, one may struggle with whether he or she is still a parent. Even if there are other siblings, parents have asked, "If I couldn't save him, what good am I to my other children?" In situations where a child experienced a lengthy or chronic illness, the parents' total focus and work may have been caring for the child. Often these parents face the question, "What do I do now that the most important work of my life is over?" They are not only coming to terms with the death of the child but must also face re-entry into society and/or the workplace in the midst of physical and emotional exhaustion.

For hospice and palliative care professionals working with bereaved parents, it is important to be alert to this important aspect of grief. There may be some parents who do not search for meaning, either because their assumptive worlds were not challenged, or because they choose not to do so. But for those who do try to make sense of the death of their child and cannot, this can be a complicating factor in their grief process (Neimeyer, 2001; Davis et al., 2000). Our task is NOT to impose our own sense of meaning but to encourage parents to explore this for themselves and know resources for referral when needed (especially if parents are searching for meaning and cannot find it).

How then can families best be supported around spiritual issues and meaning-making in the death of a child? One strategy suggested by the American Academy of Hospice and Palliative Medicine is the mnemonic LET GO (Storey & Knight, 2003). While developed for hospice and palliative care physicians to address spiritual issues, the strategy is appropriate for other members of the health care team, including spiritual care providers and bereavement professionals. In this approach, health care professionals are encouraged to:

Listen
Encourage the search for meaning
Tell of your concern

Generate hope
Own your own limitations

The healing power of *listening* cannot be underestimated. Health care professionals may feel a sense of helplessness that they cannot fix the situation or even take away the parents' pain but in allowing the story to be told, the unfolding of the narrative itself can be healing. Staying present to families experiencing raw grief can be incredibly difficult and often in hospice and palliative care training, health care professionals are urged, “Don’t just do something, stand there!”

The next recommendation is to *encourage the search for meaning* (without imposing our own). This approach is not for the immediate time of death, unless the family themselves raise it as part of their coping (trying to find benefit or make sense of the death too soon can add further anguish to the family). Neimeyer recommends that we encourage people to tell their stories and listen for “quality terms” usually described as similes or metaphors: “Grieving is like…” (Neimeyer, 2006). One bereaved father described how he found benefit in the years after his daughter’s death by using the following image: “It was like our life was on track for a superhighway—my wife and I had good jobs, a nice house, four kids—and we were moving quickly on that nice road. After death of our daughter, it was like we were detoured into a dark forest and sometimes it was hard to even see if there was a path to move forward. Gradually I realized that winding dirt path we were on in our grief journey was running parallel to the superhighway but on our path we moved slower, we took time to really be involved in our kids’ lives, and we learned to appreciate the little things.” One study found that the most significant predictor of finding meaning for bereaved parents was attending a bereavement support group (Murphy & Johnson, 2003), further evidence that outside supporters can help facilitate the search for meaning.

Another way to provide spiritual support is to *tell of your concern*. Health care professionals often wonder if it is appropriate to reach out to families, to show their own emotions. Studies reveal that parents appreciate acts of kindness and authentic expressions of sadness or grief (Macdonald et al., 2005). Even a basic acknowledgment of the child’s death through a sympathy card, telephone call, or attendance at a service can be comforting and supportive to the family (Macdonald et al., 2005.)

In suggesting health care professionals *generate hope* for families, parents could be asked, “How will you live in such a way to honor your child?” Many parents find that it is important that their child be remembered in some way. It may be as simple as using the child’s name and sharing memories. Parents also hope that their child’s life and death made a difference in the world. Health care professionals can assure parents of this by acknowledging the on-going legacy that a child leaves through memories or changes in health care practice.

Finally, health care professionals are encouraged to *own your own limitations*. As noted, the inability to find meaning can be a complicating factor in bereavement (Davis et al., 2000). It is important also that health care professionals know how/when to refer families who may be struggling with this aspect of grief. Owning our own limitations also means that health care professionals can manage their own grief. How do we make sense of the fact that we live in a world where despite our best medical efforts, some children will die? When I first started in my role as Bereavement Coordinator at our children’s hospital, one physician remarked, “If we need you, I must not be doing my job.” Approaching death as a medical failure is an incredibly heavy burden to bear. Looking back at ways we cared for patients, promoted healing, and made a difference in patients’ and families’ lives can help us manage our own grief. In fact, Papadatou has developed a model of grief for health care professionals based on her work with pediatric physicians and nurses. It includes recognition that for health care professionals, grief from a patient’s death may be related to several factors: the loss of the patient, identification with the parent’s pain, loss of our own assumptions about our worldview, threats to our own personal mortality, previous personal losses, and loss of professional integrity (Papadatou, 2000). She suggests interventions that focus on clinical information, emotional support, and opportunities for meaning-making such as rituals and remembrances (Papadatou, 2000).

Researchers are also interested in whether finding meaning is itself an outcome for the bereavement period or simply a way to reduce the risk of poor outcomes for health and adjustment (Murphy et al., 2003). For parents, the search for meaning does seem to be a central aspect of grieving and it is important for health care professionals to educate themselves about how to encourage and support families who do choose to engage in this search.

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SPIRITUAL CARE OF CHILDREN WITH LIFE-LIMITING ILLNESS

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Assessing and Understanding the Spiritual Concerns of Children

Assessing and understanding the spiritual concerns of children begins by understanding the language children use to express spirituality. For children raised in a specific religious tradition, their spirituality is often expressed best in the language and rituals of their specific tradition. Discussions about prayers, sacraments, traditions, and worship help professionals understand the role of religion in the child's life. During these discussions, practitioners may want to listen for pauses, questions, or perhaps even puzzled looks that indicate a child is questioning his or her religious beliefs in light of the experience of illness.

Spiritual care assessments are often problem focused—attempting to a uncover conflicts or unresolved issues in a child's spiritual life. This approach is especially common in hospital settings that rely on problem-oriented charting. However, the best spiritual assessments are those that allow a child to tell narrative stories that do not focus on problems. Narrative stories can be an invitation to enter into a child's spiritual world of inspirational and life-giving stories, not just problems.

Verbal conversations about abstract spiritual concepts may be discussed more fully after a child has had an opportunity to express him or herself in other ways including art, music, activity, play, or music. These other modalities allow children to have fun while they explore serious topics. If there is one critique of pediatric spiritual care, it is that it often does not involve enough play. The laughter, experimentation, and engagement of play may be exactly what are needed to explore serious topics.

In addition to religious beliefs, children often want to explore spirituality in broader terms as they work to understand the meaning of their illness. Children living with life-limiting illness often want to address spiritual issues of unconditional acceptance, forgiveness, hope, safety, loneliness, and ethics.

Unconditional Acceptance

Children who have undergone therapies, chemotherapy, and radiation, all of which have failed to stem the disease process, may not understand that they are unconditionally accepted. Words such as, "he failed the protocol" or "she is deteriorating," inadvertently may communicate to a child that he or she has let down parents and doctors alike. All children need to experience unconditional acceptance, especially those who have fought their illness unsuccessfully. Children need to know explicitly that love for them is not dependent on getting better and that the course of their illness does not have anything to do with what they have done or failed to do.

Forgiveness

Children are raised to understand the difference between right and wrong. Children may need to be forgiven for something we consider trivial in relation to their illness such as being impolite to a brother or sister. Reassurance given too quickly, or a need dismissed as "it's nothing, don't worry about it," may cut off chances for a much deeper conversation about regrets, guilt, or remorse.

Hope

Adult often conceive of hope in terms of cure or medical improvement. In contrast, children's hopes are often more focused on the present or the near future. For children, hope may have to do with the desire to go to the playroom in the afternoon or just to be able to get out of bed today. Rather than wishful thinking, hope might be better thought as "what you strive for." This definition of hope has enough room to hope for a visit to the playroom and to hope for a miracle cure.

Safety
The unpredictability of illness can make a child's world seem very unsafe. Caring for children's spiritual needs should include helping them to find a future that provides a safety and security. Often when children speak about heaven or the afterlife, their primary concern is who will take care of them—God, or a relative who has already died, for example. Concrete explanations of heaven that include explanations about who will take care of them can address children's' need to feel safe and cared for.

Loneliness
Obvious times of loneliness are those times during a hospital stay when parents are not able to be in the hospital due to family demands or fatigue. Less obvious is the loneliness experienced by children because they cannot participate in school, scouts, their church, synagogue, or mosque activities, or see neighborhood friends. Visits by parents and friends are important sources of spiritual renewal for children. Sometimes arranging a visit by a group of school friends can be more spiritually uplifting than any other intervention.

Ethics
Ethical questions during a life-threatening disease are often thought of as questions about resuscitation, experimental protocols, or treatments that are futile. Children often have ethical questions, but their ethical concerns are expressed in a much simpler language. "I don't want to get this shot," could be heard as just whining or could be heard as an ethical question about whether the treatment is worth it. Children engage in ethical decision-making when they judge the impact of treatment on their immediate concerns such as the ability to attend school or other activities. Professional's willingness to help them with day-to-day concerns can lay a foundation for helping with future ethical decisions.

Providing Spiritual Care to Children

The hospital or hospice chaplain has the explicit job description of providing spiritual care. It is perhaps more accurate to say that the chaplain has the responsibility to articulate spiritual concerns and to assist the team with the provision of spiritual care. It is unrealistic to think that every chaplain will be skilled or comfortable providing care to children. If so, the chaplain may act as a consultant on spiritual matters to others who are more experienced in the care of children.

Local clergy may provide spiritual care more effectively. Local clergy know not just who the child is now, but who he or she has been throughout his or her life. Clergy also represent more than just themselves. They are a connection to a broader faith community. The spiritual, emotional, and concrete acts of support from a congregation are an important source of support for many families. In addition, in many religious traditions, ordained local clergy have the primary role in performing sacraments and religious rituals.

Although the chaplain most often takes the lead in providing spiritual care, it is the team as a whole that has responsibility for meeting the spiritual care needs of the family. All team members can contribute to spiritual care by remembering to focus on strengths, by reflecting on the possible meaning of each experience, and by contributing the unique gifts of each team member. Spiritual care is best delivered when it is incorporated into all care, not when it is provided as a separate service.

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PIP AND THE EDGE OF HEAVEN: A REVIEW

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Pip and the Edge of Heaven (E. Liddle; Oxford, England: Lion Publishing, 2002; Grand Rapids, MI: Eerdmans Books for Young Readers, 2003) shares the story of Pip, a little boy with big questions. He asks his mother about heaven, but before mother can answer, Pip offers his own ideas about heaven and life after death. As Pip grows, his questions recur and again answering for himself, we see his understanding grow and deepen. Pip's mother responds to Pip's own insights with love and support. Besides offering a gentle story of spiritual exploration to share with a child, this book reinforces to parents and caregivers that a child's developmental state will influence the child's understanding of spiritual concepts. The adults' job often is not to have all the answers, but to support and guide the child's own exploration.

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SOME FRAMEWORKS FOR UNDERSTANDING LIFE AND DEATHIN SELECTED EXAMPLES OF CHILDREN'S LITERATURE

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An important subject that often arises in discussions of religious, spiritual, or existential matters concerns the large-scale frameworks that individuals and groups use to understand and explain the relationship between life and death. Here are ten examples of literature written for children that address these subjects. Adults can give books like these to young readers who are confronted by a life-threatening illness or a death of someone they love. Another—perhaps better—approach would be for adults to read books like these along with children and engage in discussions of the issues they raise with those children.

Annie and the Old One (M. Miles; Boston: Little, Brown, 1971) offers a Native-American version of the view that death is a natural part of life. Here, her grandmother tells a 10-year-old Navajo girl, "When the new rug [that the girl's mother is weaving] is taken from the loom, I will go to Mother Earth." To forestall that unwelcome event, Annie tries to unravel the weaving in secret and to distract her mother from weaving. Annie misbehaves at school in the hope that her teacher will call for a meeting with her mother and she lets the goat and sheep out of their pen so that time must be spent rounding them up. Eventually the adults realize what is going on and Annie's grandmother explains that we are all part of an inevitable natural cycle. When Annie realizes she cannot hold back time, she indicates that she is herself ready to learn to join in the weaving.

Annie and the Sand Dobbies: A Story about Death for Children and Their Parents (J. B. Coburn; NY: Seabury Press, 1964) is a story about a young boy named Danny who encounters the deaths of both his toddler sister from a respiratory infection and his dog after it ran away from home and is found frozen to death. The author, at the time the Episcopal bishop of Massachusetts, introduces a neighbor who uses imaginary characters to suggest that the deceased are safe with God.

Beyond the Ridge (P. Goble; NY: Aladdin/Simon & Schuster, 1993) is a Native-American story that describes the moment of the death of an elderly Plains Indian woman. While family members prepare her body according to their custom, the woman experiences the afterlife believed in by her people as she makes the long climb up a difficult slope to see the wondrous Spirit World.

First Snow (H. Coutant; NY: Knopf, 1974) emphasizes that life and death, though different, are, in truth, two parts of the same reality. In the story, two events dominate the life of Liên, a young girl who has recently come with her family from Vietnam to live in a small town in New England. Liên is impatiently waiting to experience snow for the first time when she overhears her parents say "Grandmother is dying." No one really answers Liên when she asks, "What does it mean that Grandmother is dying?" Finally, one day her grandmother tells Liên to go out into the garden and hold her hand up to heaven in order to discover for herself what dying means. When a snowflake lands on her finger, Liên appreciates it as a tiny, fleeting thing, beautiful and delicate. Then when the sun causes the edges of the snowflake to burst into a thousand tiny rainbows, it changes to a drop of water and falls on the ground where it nourishes a tiny pine tree. All of this affirms Liên's Buddhist beliefs that life and death are but two parts of the same thing.

The Great Change (G. Horn; Hillsboro, OR: Beyond Words Publishing [20827 NW Cornell Road, Suite 500, Hillsboro, OR 97124-9808; 800-284-9673], 1992) is a Native-American story in which a grandmother explains to her nine-year-old granddaughter that death is not the end of everything. It is the Great Change, part of the unbreakable Circle of Life in which our bodies become one with Mother Earth while our souls or spirits endure.

Hope in Heaven (C. Barreras; Folsom, CA: Hope in Heaven [P.O. Box 874, Folsom, CA 95763; www.hopeinheaven.org], 1998) is a slim booklet that tries to show how one might talk about the possibility of death to a child with a life-threatening illness. The first portion of the text insists the child is important and is loved, and promises that no one will give up the fight, even while admitting that things do not always turn out as we might wish. The remainder affirms God's presence and the expectation of a heaven to come.

The New King (D. Rappaport; NY: Dial Books for Young Readers, 1995) describes what happens when Young Prince Rakoto cannot accept the death of his father. He commands court officials to bring his father back to life—something that, of course, they are unable to do. At that point, a Wise Woman intervenes to explain that when the earth was new God gave the first human couple a choice. God said, "One day you must die. When it is your turn, do you want to die like the moon or like a banana tree?" The moon starts out like a sliver, grows bigger and bigger until it is full, then gets smaller and smaller until at last it disappears, only later to begin to grow all over again. By contrast, the banana tree grows and sends forth shoots. When the tree finally dies, the shoots keep growing until they are big enough and strong enough to send out their own shoots. At first, the man wanted to die like the moon so as to come back to life and live forever, but the woman persuaded him that it would be better to live, love, and die, while one's children carry on—and thus to find a way of living forever by giving life to others. Realizing the lessons and legacies that he had been given by his father, Prince Rakoto then determined to rule "with love and justice as his father had taught him, and he passed his father's lessons on to his children."

The Next Place (W. Hanson; Minneapolis: Waldman House Press [525 North Third Street, Minneapolis, MN 55401], 1997) uses text and art to suggest in a serene and comforting way how different we will find the next place we go to after death by contrast with the place we now inhabit in this life.

Winter Holding Spring (C. Dragonwagon; NY: Atheneum/Simon & Schuster, 1990) describes the great pain that 11-year-old Sarah and her father experience after Sarah's mother dies. Nothing is the same for either of them. Gradually, however, they begin to share their experiences and their memories of Sarah's mother. Eventually, they realize together that "nothing just ends without beginning the next thing at the same time" (p. 11). Each season somehow contains its successor; life and love and grief can continue together. Life and death have a kind of seamless connection because winter always holds spring. And Sarah knows that "love is alive in me and always will be" (p. 31).

Another book offers a kind of anthology of stories about life and death that have arisen in different human communities. Adults can read this book for their own benefit or as a basis for sharing some of its stories with children

Some Folk Say: Stories of Life, Death, and Beyond (J. H. Gignoux; NY: FoulkeTale Publishing, 1998) brings together 38 legends, retold in prose and poetry, that different cultures have used to come to terms with the reality of death and hopes for life beyond the grave. The stories are grouped under five headings: origins of death; balancing life and death; lessons for life; after death; and reconciliation with death. Brief comments from the author introduce each section and follow each story. The book is also enlivened by 8 dramatic illustrations. A treasury of global culture to stimulate the imagination and to use in working with children.

REMARKS

Stories like these are tools that can contribute to the search for the meaning of life in the face of death. They offer opportunities for children to learn about spiritual issues and for adults to share their spiritual values with children. Children may absorb what these books have to offer about spirituality when they read them on their own, but that process may be enhanced when a child reads and discusses these books in the company of a caring adult or in the context of a children's bereavement support group that is led and facilitated by a knowledgeable and sensitive adult guide. In such discussions, children and adults are not captives of storybook authors; instead, they can draw upon the resources of a particular story while also using it as a springboard to work out their own ideas and beliefs, and to share them with each other.

These books recognize that children need reliable information and guidance in understanding and exploring the meaning and spiritual implications of death-related events. They also legitimize children's questions about these subjects. Several books acknowledge the limits that children and adults might encounter in seeking to understand death-related events, as well as the appropriate role of faith, hope, and trust when one reaches the limits of knowledge.

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For additional information about death-related literature for children, contact the Centering Corporation, P.O. Box 4600, Omaha, NE 68104-0600; tel. 402-553-1200; fax 402-553-0507; www.centering.org; e-mail to Centeringcorp@aol.com).

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Items of Interest: In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. Subjects and Contributors for Future Issues.

In past issues of this newsletter, we have addressed a wide range of subjects, including bereavement, sibling bereavement, self care, ill and dying teens, perinatal loss, neonatal loss, and perspectives of fathers and other males. In this issue and the next one to follow, we are focusing on various aspects of spirituality as they may relate to pediatric palliative care. Beyond that, we are contemplating an issue on the many specialists and members of our interdisciplinary teams who contribute so much to pediatric palliative care (such as child life specialists, speech and massage therapists, OTs, PTs, social workers, art/poetry/story/music therapists, lay volunteers, and others).

For the next issue on **spirituality,** we already have in hand several articles and promises of additional pieces to come. But we would welcome more contributors, in particular those who could write about spirituality and PPC as it goes beyond mainline Western religious perspectives and/or from nonreligious or philosophical points of view. Beyond that, we are considering what might be included in a forthcoming issue on **volunteers and professional specialists who contribute to the work of interdisciplinary teams in PPC**. If you know of good topics and/or contributors (including yourself) for these and other future issues of this newsletter, please do not be shy! Step right up and contact any of the following: Christy Torkildson at torkc@sbcglobal.net; Mary Kay Tyler at mktyler@hospicewr.org; or Chuck Corr at charlescorr@mindspring.com. We will work with you!

2. Help Needed with Calendar of Events

Several recent issues of this newsletter have featured a section on Educational Resources compiled by Karen Paradise Baranowski. Karen has also contributed items of interest (such as upcoming events and conferences) to a calendar of pediatric educational opportunities (available at www.nhpco.org/pediatrics). Unfortunately, Karen has recently been obliged to give up these responsibilities. We thank her very much for her splendid work on behalf of us all. And now we need to seek one or more volunteers to take up these responsibilities on behalf of the newsletter, its readers, and the ongoing calendar. In the absence of one or more such volunteers, we have not been able to include the Educational Resources section in this issue and will not be able to do so in the future.

3. Opportunities to Take Part in the Activities of Two ChiPPS Work Groups.

The newly-renamed **Communications Work Group** of ChiPPS (previously known as the Education Work Group) is tasked with continuing the development of the ChiPPS e-newsletter, as well as overseeing and developing content for the ChiPPS Web page, providing resources for NHPCO's InfoCenter, and monitoring the Pediatric Palliative Care listserve which will debut later this year. The Communication Work Group is a multidisciplinary group including parents, nurses, physicians, chaplains, social workers, and psychologists. The Work Group welcomes participation by all who are interested in pediatric palliative care. For further information please contact committee Co-Chair, Christy Torkildson at torkc@sbcglobal.net.

The newly revamped **Education Work Group** of ChiPPS seeks new members. This group will work to develop educational resources for NHPCO and advocate for quality programming around pediatric palliative care issues. This Work Group is charged to provide ideas, speakers, and content for NHPCO conferences, review session proposals for peds content for all conferences, plan audio-conference seminars, propose on-line courses with Mount Ida, and update ChiPPS educational materials and resources. The Education Work Group also works with Caring Connections to develop educational resources and Partnering For Children campaign. We welcome participation by those interested in pediatric palliative and hospice care. For further information, or to indicate your interest, please contact committee chair, Stacy Remke, by email at: stacy.remke@childrensmn.org or by phone at 612/813-6328.

4. Pediatric Palliative Care at Access Conference.

ChiPPS is proud to have created an educational session track that is part of NHPCO's 2nd National Conference on Access to Hospice and Palliative care being held in Minneapolis, MN, August 18—20, 2008. Conference registration has not yet begun but we encourage you to check your calendars and try to join us in Minneapolis this summer. More information about the Access Conference will be available soon on NHPCO's Web site, www.nhpco.org/conferences.

5. Support Partnering for Children/Wear a Bracelet.

Partnering for Children (http://www.partneringforchildren.org/) is a national awareness campaign that was launched last December at the Clinical Team Conference. The goal of Partnering for Children is to help get the word out about compassionate, family-centered healthcare for children with life-threatening conditions. The ChiPPS work group and the resources ChiPPS makes available is an important part of this campaign.

In the memory of the many children whose wisdom and courage inspire us, inspirational bracelets developed by Children's Hospice and Palliative Care Coalition are now available through Partnering for Children. These inspirational bracelets which bear poignant messages from children can be ordered directly online at partneringforchildren.org or by calling 800/646-6460. One hundred percent of the net proceeds of these bracelets go directly to improving care and quality of life for children with life-threatening conditions.

For more information on the Partnering for Children campaign, including how to join as a campaign partner, please visit http://www.partneringforchildren.org/.

6. New ChiPPS Listserve

A new Pediatric Palliative Care Listserve being established by ChiPPS will debut later this year. This new list will be available to all ChiPPS and NHPCO members. Current recipients of the ChiPPS e-newsletter will automatically receive information about the listserve. If you are not a current recipient of this e-newsletter, you can join the distribution list and receive information about the listserve by going to: www.nhpco.org/pediatrics and clicking on the link to join the newsletter e-mail distribution list -- there is a simple online form that we ask you to complete. We are always happy to welcome people interested in pediatric palliative care.

7. NewsLine/Insights.

The December 2007 issue of NHPCO's member newsletter, *NewsLine/Insights* focused on caring for children and their families and included articles written by members of NHPCO's National Council of Hospice and Palliative Professionals (NCHPP). Members may download this issue in PDF from the NHPCO Web site at www.nhpco.org/newsline.

Visit the ChiPPs Web page at www.nhpco.org/pediatrics for further materials and resources of interest.

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