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Issue Topic: Spirituality and Pediatric Palliative Care

Welcome to the eleventh issue of the ChiPPS electronic newsletter. This e-newsletter links to a PDF collection of articles contributed by family members and professional colleagues. 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.

Comments about the activities of ChiPPS, its Communications Work Group, or this issue of the newsletter are welcomed. We also 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 #11: 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.)

Faith & Family: Religious Rituals when a Baby or Child is Dying

p. 4

Ann Fitzsimons

We work with families who are losing children...some before birth, some at birth, and others from toddlers to teens...To quote a familiar Bible passage..."And a child shall lead them." And as we all know, they usually do. I share with you now the story of our faith-filled, end-of-life journey with my infant niece, Riley Ann. (See also a related article in issue #8 of this newsletter, dated August 2007, and a portion of the fourth article in this issue.)

The Incredibly True Adventures of Dylan

p. 8

Barbara Seyda © 1998

"There once was a spirit-boy who rode on the back of a giant turtle..." This is a poignant story written by his aunt and inspired by the short life of Dylan and the legacy he left for family and friends. (See also a related article in issue #8 of this newsletter, dated August 2007, and a portion of an article in issue #10, February 2008.)



On the Beach

p. 10

Kathy Wandishin

We often hear of connections with a child or loved one who has died and wonder. In this piece Kathy shares the story of her son Johnny's journey; with heartfelt honesty she tells of the struggles that have "taken a lifetime" and shares her comfort in the "belief in our son's new life in eternity".

***Relationship of Spirit: Deceased Children and Their After-Death
Communications with Loved Ones***

p. 13

Ann Fitzsimons, MBA, and Leslie Feret, LCSW

"The stories that families have shared with us often tell of ways that their children have communicated to them, including signs or symbols they can see/smell/hear/feel and that only could be attributed to the child, through dreams or visitations, or through strong intuition—a "knowingness" that their child is near or reaching out to them in some way." In this piece Ann and Leslie describe some of these stories and offer some concrete suggestions about how to work with families sharing these experiences. (Note: portions of this article refer back to the first & second articles in this issue.)

The Spirituality of Compassionate Presence

p. 18

Mark Power, BCC

Mark asks a powerful question, "Can we open ourselves to the uncertainty of the moment?" He goes on to say, "If we do, and allow ourselves to become vulnerable, we join with another on their path and thus bring them into community—they are not alone." Is this not a hallmark of our work? Mark explores presence, the opportunity to have an impact on healing, hope, and peace.

Faith Communities: A Hand of Mercy

p. 21

Randy Johnson, M.Div.

Randy provides practical suggestions on how to incorporate faith communities in the care of a child and family and offers "some ideas any faith community may incorporate to lessen this burden for their parishioners and others."

Assessing Cultural and Religious Diversity in Pediatric Palliative Care

p. 23

Rev. Paula J. Teague, D.Min., BCC, ACPE, CPE Supervisor

Quality palliative care depends upon *honoring the religious and cultural diversity in our patients and families*, as well as the integration of the spiritual into the overall care plan for the children and families for whom we care. Paula explores tools to help us meet this need and offers practical suggestions to aid in the integration necessary for comprehensive care of child and family.

A Hospice Chaplain Supports a Family

p. 26

Peter Lund, M.Div.

Peter uses the story of one family to share the work of a hospice chaplain and help us realize the integral part spirituality plays in the care of our children and families.

***One Care Provider's Journey in Pediatric Palliative Care: From Nursing
to Ministry to Program Director***

p. 29

Judith Dunlop, M.A., M.Div.

Judith shares her journey from nurse, to pastor and now program director, as well as some lessons learned along the way from the children and families. There are always "daily reminders of the capacity for healing and strength within the human soul and spirit".

***Transformation and Transcendence in Selected Examples
of Children's Literature***

p. 32

Charles A. Corr, Ph.D., CT



Chuck provides an excellent selection of children's literature that explores issues associated with transformation and transcendence that often "arise in discussions of religious, spiritual, or existential matters. Here are nine examples of literature written for children that address these subjects. 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." (Note: A companion article describing other books for children that address the large-scale frameworks individuals and groups use to understand and explain the relationship between life and death appeared in issue #10 of this newsletter, dated February 2008.)

The My Wishes Document

p. 35

David Simison

David shares with us a wonderful tool that helps us "to talk to the child about what they want, what makes them feel safe and comfortable, and what they want their parents, doctors, and nurses to know." These can be difficult topics to broach and this is one tool that can help make those difficult conversations easier. From Aging with Dignity, the organization that developed the well-know advance directive, "Five Wishes."

My Comix

p. 37

Deborah Roundtree

"**My Comix** is an interactive computer game for children and teens with life threatening illnesses." Deborah shares information about the tool and how your organization may be able to pilot the game without charge.

Items of Interest

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ChiPPS customarily shares items that may be of interest to our readers.

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Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its Communication Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.



FAITH & FAMILY: RELIGIOUS RITUALS WHEN A BABY OR CHILD IS DYING

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"If God brings you to it, He will bring you through it."
-Anonymous

Introduction

We work with families who are losing children...some before birth, some at birth, and others from toddlers to teens. We know the literature on bereavement states that the death of a child is the most difficult loss a person or family may ever go through. The hospice model prides itself on treating and helping the whole family through this loss, from their physical, psychosocial, and religious/spiritual needs. But how knowledgeable are we about our families' cultures and religious rituals, and more importantly, how do we help them accomplish these so there can be no "What If's" after the child has died? We learn from other families who teach and enlighten us about their end-of-life journeys with their children. To quote a familiar Bible passage..."And a child shall lead them." And as we all know, they usually do. I share with you now the story of our faith-filled, end-of-life journey with my infant niece, Riley Ann.

Our Story of Religion and Rituals When Riley Was Dying

Riley was born with a malignant brain tumor that went undiagnosed in utero until a week before her birth at 34 weeks. Despite numerous ultrasounds (as my sister had gestational diabetes), this tumor never showed up. At Week 33, my Sister couldn't feel the baby moving much. A trip to the OB indicated tests needed to be run, the results of which were bad. The Doctors hypothesized that the baby had a stroke, or some other trauma, that had left her with very little healthy brain tissue. She likely wasn't going to survive. Discussions were had regarding delivering her early to help her, but lung immaturity made that impossible. So, we waited and put her life in God's hands. All involved in this drama were powerless to fix or change this. God had a plan for Riley, and we were going to have to watch it unfold on His timeline, not ours. At Week 34, Riley decided to grace our world. While tragic to know we were going to lose her at any moment, we held strong to our faith, and to her, to get us through. What else did we have?

We are a strong Irish Catholic family. Mom and Dad were both immigrants from "the old country." Religion and our faith were never far from the good...or bad times in our lives. The birth of Riley was no different.

When I got the news my Sister had been rushed to the hospital for an emergency C-Section, I jumped into the car full of fear as we knew the baby might not even survive the delivery. I couldn't think, I was emotionally numb, and my hands were shaking so badly I could hardly hold the wheel of the car. So, I prayed the Hail Mary, over, and over, and over again. I didn't know what else to do. After the umpteenth time of praying this prayer I'd known since childhood, a calm settled over me with a "knowingness" that Riley was going to be "OK." I knew not "OK" in the long-run, but for tonight, she was going to get through this delivery. We'd have some time with her. How long was anyone's guess.

Riley was born that night with severe hydrocephaly due to the damage the tumor had caused. While in danger, she seemed calm and peaceful in her isolette in the NICU, but it was a false calm, and we all knew it. Because it was the middle of the night, the plan was to keep her hopefully stable in the NICU,



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and then transfer her to a specialized Children's Hospital the following day. I feared for her physical being. I feared for her religious life. I feared for the "What If's" for my sister, husband, and kids that loomed large if she died tonight. How much time did we really have? How fast was the clock ticking? What needed to be done now...and by whom?

I remember thinking she needed to be baptized. It was as if I was on autopilot and all that kept coming up on the radar screen was that the religious parts of her life needed to be attended to. The medical team was taking care of her healthcare needs, but who was taking care of her religious and spiritual needs that would be important to us when she died. Yes, she was a baby, that's true, but she was part of our family and was entitled to (needed to have?) the same rituals the rest of us had been blessed with as part of our Christian faith life. A baptism was part of our religious path and would have been part of hers, had her birth been under different circumstances. But where do you find a priest in the middle of the night and no one at the hospital was offering one up. I remember needing to find the chapel—to find a place to be alone with God so that I could get some answers, or minimally, some direction. The refrain, "Be still and know that I am God." (Psalm 46:10) kept playing in my head, but how do you do this when a baby is born dying and all you really want to do is break down and weep, or scream with rage at God for taking her from us when we hadn't had any time with her here on Earth.

It was a Catholic hospital and I found the chapel. It was 3 am and I entered into the dark silence with only a few candles lighting my way. I hit my knees and just prayed for any kind of sign, answer, or sense of what to do. The answer came in the form of a white Styrofoam cup that had been left behind on the floor from another family on probably a similar "Please God" chapel pilgrimage. I rinsed it out and proceeded to fill it with holy water from the water fonts in the chapel. I brought the cup into the NICU, careful not to spill any, and blessed Riley over and over again with the sign of our faith—a cross on the forehead, much like the priest would have done if he had been there. If she were to die now, she'd be, as they say, in the Church, marked with the sign of our faith. Maybe not by a priest, but we believed that it would still "count."

The next day before Riley was transferred to a local Children's Hospital, we scrambled to have her "officially" baptized as my Sister was not being allowed to move with her due to the severity of her surgery and repairs from the C-Section. We had expressed our religious needs to the staff and they intuitively knew it was important to my Sister to be a part of this religious ceremony as it could be the last time she'd see her daughter alive. The priest showed up, but we wanted it done right—with a baptismal candle, white bib, the whole nine yards. We pulled together the various pieces from wherever we could find them in the hospital (the candle was a colored birthday candle; the bib, one they use in the nursery, and we found a smoker with a lighter to light the candle during the baptism as matches aren't plentiful in the hospital). We gathered around the isolette, my sister holding Riley's hand during the entire ceremony, and welcomed this little one into the church, with as much of the pomp & circumstance as we could muster under the circumstances. My Sister felt better sending her off having been baptized. She then turned to me and said (knowing I was going to accompany her daughter), "You'll know what to do." I prayed I would.

Days passed and Riley lived. My Sister was finally released and able to be reunited with her daughter. Additional sacraments were administered to Riley—Confirmation and Last Rites (now called the Sacrament of Anointing). While no other Catholic rituals were "required" beyond her baptism, the administration of these additional sacraments to Riley made my Sister and the family feel better that "all the religious bases had been covered," that is, that we had done all we could physically and spiritually do to send this baby back to God. My Sister and I never worried about where Riley would go when she died—the resounding answer was always Heaven—but 38 years of Catholic teachings tell you there are rituals that need to be done, even to babies, so we did.

We celebrated other religious rituals with her that we recognize were more for us than her, but which were important none-the-less. Riley was born December 19th and lived through the Christmas Season in



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the NICU, so we read her the story of the First Christmas. We serenaded her with religious Christmas carols, which held so much meaning for us. And while there was no room for Baby Jesus at the inn, there was so much room in the hearts of so many this holiday season for Riley and her family, that we knew God was with us, and with Riley. These Christmas stories and songs of our faith would never again be seen the same for us for holidays to come. We believe now that it was no accident that Riley graced and blessed us during this special Christmas so many years ago.

The last of our “religious hurdles” to cover-off was finding out about the Church’s teachings on organ donation. While we weren’t sure that Riley’s organs would be eligible for donation, we felt that Riley’s short life would have an even “bigger picture” meaning if another baby could benefit from some of her donated organs...but what did the Church think about this? My husband placed a call to our local Parish on Christmas night to try and get some answers. We’d gotten a frantic call from my sister that they were going to take Riley off the vent due to her moving and dislodging it, and we knew we could lose her when they did. The Priest spent quite a bit of time with us on the phone consoling us, but also telling us that “What greater gift could Riley give than the gift of life to another” and that yes, the Church wholeheartedly supported organ donation under these circumstances. While we ultimately were unable to donate her organs due to the cancer, we felt better we had reached out to cover this last question mark. We also felt buoyed that our faith community had responded in an incredible show of support, on a night so critical to the tenets of our faith—Christmas. The Priest took the time to “be” with us and walk us through this difficult decision, a sign that we are indeed part of a universal Church supportive of one another, especially when its members are walking the heartbreaking and lonely path of losing a child.

We found the hospital staff supportive in our mission to have these Catholic sacraments administered to Riley. No one questioned us, but instead, found priests happy to help us. And the staff even prayed with us during Riley’s baptism. I remember vividly the medics who were going with Riley in the Transfer rig praying right out loud with us when cued by the priest. It was communal, regardless of the staff’s faith life and beliefs. They prayed with and for us and Riley, and it made all the difference to us when she died.

Riley did die about two weeks later, and undoubtedly, went to heaven. Her short life was celebrated with a private family prayer service and burial, and then, a few days later, with a full Catholic Mass of Remembrance, with over 600 people in attendance. The Church was full and there were so many tears. People prayed and cried for Riley and her family, but also for all the other babies and children they had known who had died too soon through miscarriage, stillbirth, perinatal, infant and other deaths. Everyone had a story or knew someone who did, and this was an opportunity to collectively mourn and pray for all the children who had died, and to celebrate that they too, like Riley, were united with God in their heavenly home.



Riley’s baptism.



Parting Thoughts

While ours is a story of a faith steeped in Irish culture and Catholicism, the lessons hopefully can be applied to other cultures, heritages, religions, and spiritual beliefs. Froma Walsh and Monica McGoldrick in their book, *Living Beyond Loss: Death in the Family* remind us that "Helping family members deal with a loss often means showing respect for their particular cultural heritage and encouraging them to actively determine how they will commemorate the dying and death of a loved one." They then go on to offer that it's important to ask several questions about a particular cultural group's religious/spiritual beliefs and customs, including:

1. What are the prescribed rituals for handling dying, the dead body, the disposal of the body, and rituals to commemorate the dying and eventual loss?
2. What are the group's beliefs about what happens after death?
3. What do they believe about appropriate emotional expression and integration of a loss experience?
4. What are the gender rules for handling the dying and the death?

Educating ourselves about the diverse cultures and religious/spiritual beliefs and rituals of the populations we serve will make us better able to support our families who are losing children. Also, asking the key questions and then helping to facilitate what the families' culture/religious/spiritual needs and desires are will presumably bring them peace of mind and soul at the child's death, and afterwards. While we can never take away their pain, we can hopefully lessen it by our actions in these faith-based parts of their lives.

The cover of Riley's Memorial Card contained a small picture of her footprints and these words which are a testament to our faith in a loving God, even when he's taking one of our (and His) children home. "Some people only dream of angels. We held one in our hands." May the journey of all those families losing children that we each have yet to meet be as blessed and as spiritually-fulfilling as the one we walked with Riley in faith, hope, and love.

References

Walsh, F. & McGoldrick, M. (Eds.). (1991). *Living Beyond Loss: Death in the Family*. New York: W.W. Norton & Company, New York. 1991. pp.178-179.

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THE INCREDIBLY TRUE ADVENTURES OF DYLAN

Barbara Seyda © 1998
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There once was a spirit-boy who rode on the back of a giant turtle. He ate gingersnaps for breakfast and sang as the sun came up. His friends were raindrops and melting snow and he kept grasshoppers in his pockets. One day his mother, the Empress, called him from a land of cinnamon-colored rocks. She was a beautiful woman with strong legs and her heart wrapped around him from a distant land. For nine months, he migrated to her with herds of caribou and Alaskan whales. He heard his father's flute and dancing feet. Their love for him sprouted like yellow daffodils and purple crocus. He watched his mother's hands and felt her heartbeat. He listened to their voices at night. They read him stories and baked him chocolate cake. While he pulled and laughed and kicked, he memorized the contours of their souls. Their love for him was like a forest of trees where he played like a prairie dog. His mother and father were an ocean of endless waves of tenderness and compassion.

Together they welcomed him into this world. One day, when the temperature was just right and there was a rainbow in the sky, he was born. He was a miracle boy and had traveled the distance of stars. He slipped into the world like a baby otter. He had coral-colored skin and black, silky hair. His feet were ticklish and he longed to tap dance. His lips were shaped like a tulip and he knew how to speak Yiddish and Polish. He knew the size of his father's running sneakers and the smell of his morning coffee. He opened one eye and saw his grandparents. He knew they had come a long way to be with him. He understood the presence of his aunts and felt the prayers of uncles and cousins. He was connected to a labyrinth of tubes to help him breathe, to circulate his blood. He knew he was here for a special time. It was a time of great celebration and everyone wanted him to stay. He carried messages of love to everyone. His family wove an iridescent blanket for him—a blanket made of the threads of life. They leaned over him, cradling his head and covered him with kisses like small butterflies.

In the night, he saw pictures falling from everyone—like snapshots out of a cardboard box. They were pictures of families in a living room, backyards with swing sets, slides, swimming pools, paper plates with baloney sandwiches, graham crackers, banana ice box cakes, Babar sitting in a rocking chair, bicycles in the drive, fishing poles, basketball hoops, refrigerators filled with snacks, soccer balls, storybooks, sets of encyclopedias, baby carriers and athletic trophies.

And then one day, a huge wooden door opened and all of his ancestors gathered around him. Grandma and Grandpa Seyda, Dzia Dzia, Ciotka, Frida, Grandpa Max, Grandma and Grandpa Kowalik, Busha, Uncle Jack, Uncle Bruno, Uncle Charlie, Aunt Mae and Uncle Lloyd. He knew they were here to greet him. He smelled golemki and kieszka and smoked Polish sausage. Everyone was wearing hand-made jackets with red trim and gold buttons and was dancing to accordion music. There was a dog, Fergie, waiting for him. Everyone picked him up and threw him high into the air like a small balloon and he fell back into their arms smiling.

Now, he begins each day making homemade ice cream and crème brulee with his dad. When his mother has a pot of risotto on the stove, he stirs it without her knowing. He sits on his grandmother's shoulder at the slot machines and whispers in her ear. He rides in the cart with his grandfather on the golf course in Las Vegas. He reads the sports page with his grandfather in St. Louis. He invents new moves during late night Sequence with his Aunts MJ and Maggie. He hides underneath Uncle James' bed at night and shares his dreams while listening to Shania Twain. He takes naps with Uncle John and Aunt Shannon under colorful Pendleton blankets. He leads Aunt BJ and Diana on hikes through the desert to a baby hawk sitting high in an old saguaro. He goes to the beach with Uncle Tim and Aunt Sam and spends all



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afternoon making sandcastles with Karly. He plays hide 'n seek in Bryce Canyon with Uncle Mike, Aunt Cindy, Rickie, Jackie and AJ.

Gold pennies fall from his hands and he knows the secrets of love. Whenever anyone misses him, he says, "Take a deep breath and know that I am you. We are all one."

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ON THE BEACH

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The phone rang once at 11 a.m. on a September Saturday morning. I checked the caller ID and the number displayed was my sister's. Wondering why Patty would begin to call me and then hang up, I dialed her back. When she answered the phone, I asked her if everything was OK and she said yes, but she had been up since 4 a.m. that morning and was stunned by a dream she had. She had hung up because she had lost her nerve, worrying that I wouldn't believe her. Patty proceeded to tell me about her dream, but she described that it was more like a vision because the detail was so real. She said she was on the beach and met my son, Johnny. He was tall, with full dark brown hair, freckles, wearing a tee shirt and shorts and was radiant with health. He looked nothing like the frail, cancer ravaged teen who had died in June. However, when she looked into his eyes, she recognized that it was indeed Johnny. He greeted Patty and asked her to give me a message. He said, "Please tell my Mom that I have arrived on the beach. I am all better and everything is wonderful here. Nothing bad ever happens in this beautiful place. Tell her that I am so grateful that she took such good care of me when I was sick and that I will always watch over her and help her while she is still on earth. Tell her when she misses me, she just needs to close her eyes and go to the beach and I will be there."

After hearing my sister's account of her dream, I knew without a doubt that our beloved son was fine. His father and I were not able to keep him safe from harm on earth, but Johnny used my sister to let us know that he had arrived on the other side and his Creator was caring for him in our place. When Johnny was dying of leukemia, he would often close his eyes while waiting for the pain medication to ease his discomfort and imagine himself in his favorite place – on the beach. I am convinced that Johnny's piece of heaven is the place he loved most during his short time on earth. His message to me through my sister's dream was all I needed to reassure me that Johnny was well and happy!

Our belief in our son's new life in eternity has taken a lifetime to cultivate. My husband Jim and I were both raised Catholic, growing up in similar traditional Catholic homes. We married in a Catholic Church and it was never a question that we would bring our children up in the faith. When our children were born, we had them baptized, took them to church every Sunday and taught them to pray. It was a very simplistic and predictable way of relating to God. As long as we did our thing, God would do his. We would teach our children to be good Catholics and love God, and God, in return, would watch over us and keep all of us safe. For many years we lived a happy and uneventful existence, raising our children in our bustling, loving home. We were blessed and thankful that life seemed relatively easy and without hardship. God was most definitely doing his part.

Eleven years into our marriage, our uncomplicated life careened in a different direction. My father suddenly took ill and died at the age of 56. Several years later we suffered a house fire and our family was displaced for four months. A few years after we had moved back into our home, Jim lost his job of 17 years with a bank and was unemployed for six months. As each trial came our way, we wondered what had happened to our neat little arrangement with God.

Then on February 16, 2000, our 10 year old son Johnny was diagnosed with acute myeloid leukemia. We certainly had not been strangers to hard times in recent years, but nothing could have prepared us for the heartache of having our youngest child diagnosed with a life-threatening disease. We felt confused and betrayed. Our family had already suffered greatly. God didn't seem to be around to prevent the fire or Jim's job loss. We felt forgotten. The thought of watching our son suffer from the harsh and toxic cancer treatment was agonizing. The thought that he might die was unbearable.



While we attended to the details of Johnny's admission to the hospital and the care of our other four children, word had spread and people everywhere vowed to pray for our son. His name was added to prayer lists all over the country and even overseas in Ireland and Germany. Church friends sent holy water from Lourdes and relics from St. Peregrine, the patron saint of those suffering from cancer. Our parish priest came to anoint Johnny with the sacred oil of the sick. So many wonderful people offered their prayers, gave us symbols of their faith, and encouraged us, and yet I felt angry and was completely in denial. I knew that this kind of pastoral treatment was reserved for the very sick, usually for people who might be facing death. I refused to believe that Johnny was that ill. Surely, this disease wasn't that serious – people get cured from cancer all the time. Besides, the doctor who gave us the diagnosis assured us that it was curable. Why are all these people making such a fuss? Johnny doesn't need all these prayers. I felt that God had been absent for the last several years anyway. Johnny could beat this on his own.

About three weeks into treatment, an event occurred that would forever transform my relationship with God. Johnny had been tolerating the chemo fairly well. He was nauseous and tired, but he was finally out of pain and was beginning to become accustomed to the hospital routine. Late one night, Johnny was unusually restless. After checking his vital signs several times, the doctor on call explained that they needed to take Johnny to the ICU. His blood pressure was seriously low and they needed to monitor him more closely. The following days were some of the most tortuous and agonizing days of my life. Johnny continued to worsen. His body swelled with fluid and he was in renal failure. It was discovered that his heart was failing, probably as a result of one of the chemo drugs that was administered. Family and friends came up to see him, fearing it might be the last time. Jim and I kept vigil by his bedside and the rest of our family hung out in the little waiting room down the hall. My fear that he would die threatened to devour me.

The hospital had allowed Jim and me to sleep in his hospital room on the pediatric floor. One night, I went back to Johnny's room and sat on the floor. The spot where his bed had once been was noticeably vacant, suggesting to me how empty my life would be without him. With tears streaming down my face, I finally and completely surrendered to God. I accepted the fact that I was not in control. It was obvious Johnny was seriously ill and might not survive and there was nothing I could do to fix it. I had learned that bargaining was not God's style. No matter what I could promise him, God had his own plan. So then and there I decided to trust him explicitly. I admitted to God that I knew that Johnny really belonged to him – that he was only on loan to us to raise him to be a responsible and loving adult. I pleaded that Johnny be healed from this latest setback and his cancer. I stated that we wanted to have more time with him – we had so much to teach him yet! I humbly returned Johnny to God and asked for strength and courage to handle whatever the outcome turned out to be, even if he did not survive. In that simple prayer of proclaiming my utter dependence on God, I had charted the course of a new relationship with the Divine that would carry me through the rest of Johnny's life and beyond.

Johnny did recover from his heart issue. He stayed in the ICU for three more weeks and finally went home. He would later undergo two more rounds of chemo and a bone marrow transplant. He achieved remission and went back to school. In April of the following year, he relapsed from his disease and we started treatment all over again. After his second bone marrow transplant he suffered with Graft vs. Host Disease. For the next five years, there would be countless hospital stays, sometimes months at a time, clinic visits, and dozens of drugs. He was admitted to the ICU several more times with life-threatening issues, but always managed to pull through. Through these years I clung to my mantra – Johnny belonged to God and was totally in his hands. I had prayed the "Our Father" prayer thousands of times. It was during this time that the line "Thy will be done" became profoundly intimate.

When Johnny decided that there were no more options he was willing to take to treat his illness, he gallantly and peacefully accepted that he would live out the rest of his life, whatever time that was, as passionately, tenderly and lovingly as he could. His belief that God was taking care of him was evident in his peaceful attitude. With our hearts breaking, Jim and I supported Johnny's decision to discontinue



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treatment. I painfully realized that God was not going to heal my son, and my sorrow was raw and aching as I began to mourn the life my son was never going to have. I continued to grasp onto my belief that God would give us what we needed to help Johnny go home. I have never experienced a time before or since that has been as challenging, sacred, and life giving as the last seven months Johnny was among us. It was a time of anguish and wonder as we learned the most profound lessons of life from our dying child.

Johnny died early on a Monday morning, the day before his sixteenth birthday. An enormous rainbow arched across the sky, appearing to originate at the top of our roof. It was as if God sent it to light the way to heaven for our precious child.

At times, my grief has been excruciating and Johnny's absence in my life consumes me. I am steadfast in clinging to the faith that has carried me all those years during Johnny's illness. I trust that in time the sorrow will diminish and I will be consoled by cherished memories.

I still think of him every day. I wonder what he would have looked like now and what he would be doing. As I continue to travel further towards a time when the hurt melts into acceptance and peace, I take comfort in my belief that Johnny is on the beach, healthy, happy, and strong, and waiting for me to join him at the end of my journey. And I continue to trust in God that in the end, all will be well.

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**RELATIONSHIP OF SPIRIT: DECEASED CHILDREN AND
THEIR AFTER-DEATH COMMUNICATIONS WITH LOVED ONES**

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"We must assume our existence as broadly as we in any way can; everything, even the unheard of, must be possible in it."

-Rainer Maria Rilke

The human spirit is eternal. This belief is held by a millions of people and sanctioned by most of the world's major religions. When a child dies, a belief in the continuation of that child's spirit usually becomes the pivotal point from which the parents and families begin to make meaning of the death and all that led up to that death. A belief in eternal spirit becomes the key component to forming an ongoing relationship with the child, an eventual relationship of spirit. When parents are reassured by clergy and family that their child is in a good place and that he or she will always be with them, although they may not disagree, they often struggle to accept this on a deeper level. Not surprisingly, after a child has died, two of the parents' biggest questions are: "Where is our child NOW?", and, "Are they OK?" Parents long for the peace of mind to know their child is safe, their spirit whole, and that he or she is cared for in a loving place with other loving spirits. Underlying this belief, of course, is the parents' fear that their child may not be safe, may not be OK. Their questions then become: "How do I know?" "How can I be sure?"

Those of us who have had the honor to be confided in and trusted by such families have heard, firsthand, the stories of communications received after the child's death. In the public media, one has only to watch programs like John Edwards' *Crossing Over*, to hear story after story of babies and children communicating beyond the grave, providing a sense of comfort and healing to their broken-hearted families. Other families have had such experiences privately and have shared them publicly in books or articles. While not all families are able to or desire to relate such experiences, many wish for a tangible connection with their child.

The stories that families have shared with us often tell of ways that their children have communicated to them, including signs or symbols they can see/smell/hear/feel and that only could be attributed to the child, through dreams or visitations, or through strong intuition—a "knowingness" that their child is near or reaching out to them in some way. Whatever the experience, the communication is real to them and serves as a way to help them survive the grief of this most tragic of losses, the loss of a child.

Many of the parents we have worked with over the years have generously shared some of their stories with us for this article. We invite you now to enter their sacred space as they tell of their experiences.

"Follow the Bouncing Ball"



In the brief two weeks of her little life, Riley Ann never uttered a cry or sound due to a malignant brain tumor which rendered her incapable of any speech. After her death, however, Dorothy, a close friend, had a dream in which Riley appeared as a two or three year old girl in a church bouncing a rubber ball up the center aisle. Riley approached the pulpit and asked Dorothy if she had her attention. Dorothy replied that she did. Riley then asked Dorothy if Dorothy knew who she was, with Dorothy replying, “No.” Riley explained that she was “Riley Ann” and that she had a message for her Mom. “Please tell my Mom I’m okay and that I’m in a good place and not to worry about me.” Dorothy waited a few weeks before she told Riley’s Mom of the dream, unsure of how she would react. Upon being told about the dream and messages contained in it, Riley’s Mother was filled with tears of peace and joy, knowing her baby was safe and at rest. While disappointed that Riley didn’t come to her directly, she reasoned that she was still in such grief that it would probably be impossible for Riley’s messages to get through to her.

In years following this first communication, Riley made several other “trips to Earth” to let loved ones know she was with those who were dying, including her Grandma and her own Mother, six years after her own death. A bouncing ball was always her “trademark,” her calling card as a sign that she was coming to greet her Grandma and Mom on their journey home to join her. To this day, bouncing balls of all shapes and sizes are constant signs of the connection Riley has with her family on earth, and are perceived as an angelic kiss of love, light, and importantly, healing, whenever they appear.

“Hawkeye”

Jodie died of a rare pediatric sarcoma at aged 18. After he died, his mother felt that he continued to try to communicate with them. In the months following his death, his mom would often go for walks and ask for a “sign” that he was around, or she would just talk to him and say, “Where are you? What’s going on?” As she was doing this, she’d then notice something that reminded her of Jodie. One evening, she watched a particularly beautiful sunset shortly after another of her “shout outs” to Jodie. In this sunset, she felt him and his love as Jodie loved that time of day and he also died at sunset on a beautiful fall evening. Another occasion after she had called out to Jodie, a hawk came over the town where she lives, which is an unusual sight. She believed it was a sign from Jodie that he’s still with them and watching over them with love from his beautiful vantage point high above.

“Pennies and Pachelbel”

Dylan died at two weeks of age from a diaphragmatic hernia which had been diagnosed *in utero*. It was a peaceful death in the hospital in the arms of his Mom and Dad, yet their hearts were broken as they returned home without the baby boy they had loved and planned on for so long. On their first time outside since Dylan was born, his Mom and Dad took a walk in the woods to get some fresh air and just “be” in their grief. While crossing a small river in the park, a bright copper penny shone at them—a sign from Dylan. During the pregnancy, Dad had picked up many pennies while running and deposited them in a piggy bank for Dylan. Returning to their car from the walk, Pachelbel’s Canon came on the radio, another sign from Dylan. They had played this song for Dylan while *in utero* and in the hospital to help calm and soothe him. To this day, Dylan continues to make his presence known to his family with money and music. Pennies and Pachelbel are comforting memories and signs that Dylan is still with them, even ten years after his death.

“A Swan in Heaven”

Another Mom has written a book entitled *A Swan in Heaven*, in which she tells the story of her son, Danny Mandell, who died at age 16 of a degenerative disorder which started at the age of 7. Danny went from a healthy, active boy to a wheelchair-bound teenager: incontinent, unable to speak, and unable to



use his hands. However, within an hour after his death, Danny was “speaking” to his Mom telepathically, with her channeling his afterlife messages for all to be inspired by and learn from. His Mom’s first vision of him was him looking like James Dean in *A Rebel without a Cause*, dressed in jeans with a rolled-up cuff and a white t-shirt. His Mom recalls that he was wading and kicking his feet in shallow water and laughing, something he had not been able to do for years while here on Earth. Danny’s visions and messages to his mom have brought healing and insight to her, and she has found meaning-making in sharing his wisdom and sage advice with others here. While he lost his voice while alive, his Mom jokes that he certainly has found it now, and he’s using it for all it’s worth.

“Christmas Magic”

It was Christmas Eve, and Tyler’s Mom knew he was different that day. She had been charting his temp, breathing, and color, and things were changing fast. She knew she was losing him...and quickly. She had been asking Tyler to please not go and to make it to Christmas for her. Her wish was granted. Tyler died one hour after the clock struck midnight on Christmas Day.

Just before Tyler died, his Mom had reached the point where she knew there was nothing more that “Mommy” could do to make him better. Kneeling beside his bedside, she said a prayer asking God to heal her child and make him well again for her and if He could not do that, then she was putting her son’s life in His hands for God to take care of him for her. A few minutes after her prayer, Tyler’s Mom felt a very strong presence around her, as if someone were watching them from outside the window. She later felt that it was Tyler’s Angels watching over him as he prepared to transition to his new home. As Tyler took his very last breath, the lights on the family Christmas tree lit up although the plug sat disconnected on the floor. At that same moment, Tyler’s brother woke up crying, as if he knew his brother had left him.

For days and weeks after Tyler died, his brother’s alphabet toy continued to sound off on the “T” button without anyone touching it. Tyler was letting his family know he was still around and with them, despite their heartache of losing him. Two years later Tyler made another connection to his family, this time in a visitation to his young brother when he told him that a car he was playing with had been his. Tyler’s Mom wrestled with all these signs and the visitation and reached out to a counselor. The normalization of Mom’s experiences supported her belief that Tyler was letting her know he would always be with her and his little brother and began to bring her peace and acceptance of her loss.

“Spirit and Reason”

Most parents continue to experience doubt and fear, in spite of the strength of their belief in these experiences. One Dad initially responded to our request with honest ambivalence at first, regarding the death of both his wife, who died suddenly, and his daughter, who died slowly from a rare liver cancer, passing on the day before the fourth anniversary of her mother’s death.

“But no, I haven’t communicated, seen, felt, etc., anything from either of them. I know that if anything like that were possible, they’d do it. Of course, shortly after her death some things happened, or seemed to happen, but that’s an acknowledged mental phenomena. Sure, I wish they were frolicking in some golden land, but deep in my heart I know this is not true. We’re mere bags of flesh and bone, emanating from the dust and shortly to return, at least the bible got that right.”

The next message from him showed a different side when he related several experiences including being “yanked back” from the path of a motorcycle by an unseen hand after his wife’s death. Later, a disabled clock continued to cryptically chime. “The trouble with such ‘messages’ if indeed that be the case, is the ambiguity: Was it a warning? An encouragement?”



But even the most rational of minds may experience and believe the healing of such events and coincidences as the same Father writes of his daughter. "With Katy, I'm struck by the fact of how many times I have heard songs from the *Wizard of Oz* in the most unlikely places and usually timed when I'm vulnerable to it. I know that the songbook is popular and not unusual to be played in public places, but a gift shop in Jamaica? Playing on the radio while on the way to visit her grave in the cemetery?" The songs seemed to follow him to China when the first thing he heard over a loudspeaker on a college campus was the same spiritually connecting music. Also in China, the first night sky he viewed had "Orion's belt in the center of it all. That constellation represents my mother, Gwen and Katy to me...Of course, nothing can change the stars—they were not rearranged for me—but I am struck by the fact that again when I was feeling down, alone, suddenly there was that pattern of stars to comfort and relieve me."

So what would be the purpose of such phenomena? Well, it's a reminder and a catharsis. Katy's Dad writes, "To be so reminded helps me to integrate life with death, to become 'one with the Moon and the West wind' as Dylan Thomas put it. It makes me think the sturm and drang of life is not such an urgent business, that all evens out in time. It makes life worth living, and me a better person, as it takes the focus off guilt, and perceptions of their omnipresence release me to love again."

Providing Support

It is sometimes difficult to understand how best to support parents in this spiritual way. Many professionals leave this area to churches and chaplains. Author and bereavement expert, Therese Rando, in her book *Parental Loss of a Child*, alludes to these stories as part of the important meaning-making and as beliefs supporting or preventing grief adjustment. Elisabeth Kübler-Ross, on the other hand, in her book *On Life after Death*, paints a concrete picture of life "on the other side."

Louis LaGrand, Ph.D., Author of *After-Death Communication: Final Farewells*, offers supportive suggestions should a family share an after-death experience or contact they've had with their child with you. It will be important to recognize this experience within the context of the family's beliefs, regardless of what your own beliefs might be. If you dismiss the possibility of this experience, you risk damaging both the therapeutic relationship and the support from you that the family is counting on. He recommends the following three steps in supporting a family who has an after-death communication with their deceased child:

- **Step One: Validate and further explore the experience with the family.** Ask questions and honestly seek out further information to help frame the experience for the family, as well as to help legitimize the possibility that the contact could have taken place. For example, asking such questions as, "What was your child wearing?" or "Did your child speak to you and if so, what did he say?" may provide the mourner the opportunity to share their story in a safe environment in which the experience can then be normalized for them.
- **Step Two: Check for personal meaning and relevance with the family.** After the parent has shared his or her story, asking other questions such as "What do you think about this?" or "How does this make you feel?" may be the signal families need to go further and talk about their interpretation of the contact and try and make some meaning from it.
- **Step Three: If the beliefs are causing parents distress, consider alternative explanations to rule out mistakes in judgment which may be causing the family anxiety.** Assist the parent in exploring their feelings when they are unsure how to interpret the contact, and normalize the experience for the person who may feel he/she is going crazy because of the contact.



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In the words of the wisest and best pediatric doctors, "Listen to the parents and families." There are many roads on the journey of making sense and meaning after the death of a child. These phenomena, coincidences of nature, dreams visions, messages through a psychic are powerful and should be honored and believed within the context of those who experience them. These are messages to parents and families of love, healing, and reassurance that their children are OK and in good places, and importantly, that they remain connected to those on earth. As professionals, it is our gift to be able to stand witness to these families, and those we have yet to meet, as they experience this rich and bittersweet, yet often healing, process.

To see a world in a grain of sand
And a heaven in a wildflower,
Hold infinity in the palm of your hand
And eternity in an hour.

-William Blake (1757-1827)

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Family Stories contributed by: Pat Donohue, Ann Fitzsimons, Christina Hartman, Beth Seyda, and Ray Mort.

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THE SPIRITUALITY OF COMPASSIONATE PRESENCE

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In the poem "The Summer Day" by Mary Oliver (p. 94), the poet muses:

. . . I don't know exactly what a prayer is.
I do know how to pay attention, how to fall down
into the grass, how to kneel down in the grass,
how to be idle and blessed, how to stroll through the fields,
which is what I have been doing all day.
Tell me, what else should I have done?
Doesn't everything die at last, and too soon?
Tell me, what is it you plan to do
with your one wild and precious life?

In these lines Oliver seems to challenge a formalized spirituality of "prayer" while celebrating the simple presence of the ordinary. In the poem, her appreciation of a summer day is enlivened by an awareness of death.

Living life with an appreciation of its fragility triggers a profound urgency in our search for meaning and fulfillment. Our awareness of the preciousness of our children and their vulnerability often awakens in us a similar urgency. This is never more vivid than when tending families with children who are on an end-of-life journey.

Death is not something we accept in American culture as part of our view of wholeness; and when we are confronted with the death of a child, the shock and dissonance are magnified exponentially. As adults, as parents, we resist this untimely passage with every cell of our body, and feel betrayed by our deeply held beliefs.

Death opens us to an awe filled (and "awful") experience. Still, those of us who have served the dying – both children and adults – have experienced a sense of the sacred that can accompany death. Something indescribable happens around death. As caregivers we hold that sense of the sacred as a torch which allows us to traverse the dark path of grief alongside a grieving parent or loved one.

What is asked of us while companioning others who suffer along these dark journeys is profound and deceptively simple; healing happens in the presence of kindness and attention. When we lack trust in our ability to be present, our tendency may be to resort to the certainty of doctrine which can distance us from the wrenching experience of the moment and from the aggrieved. We can sound dismissive of the enormity of a uniquely personal experience, and we become lost to the present. Mary Oliver dances around the seduction of doctrine with the words, "I don't know exactly what a prayer is. I do know how to pay attention . . ." She draws from the moment a living experience of spirituality, making the present moment a journey where one is called to wonder, to look deeply at who we are, at the world, at our illness, at God/Goodness. When we open to the present in the face of suffering, we may uncover compassion. In its root, the word compassion means "to suffer with." When we "suffer with," we are sometimes invited to "hope with."

In, "The Hope of Loving," Meister Eckhart, the thirteenth-century Christian mystic says (Ladinsky, p. 109):



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What keeps us alive, what allows us to endure?
I think it is the hope of loving,
or being loved.

I heard a fable once about the sun going on a journey
to find its source, and how the moon wept
without her lover's
warm gaze.

We weep when light does not reach our hearts. We wither
like fields if someone close
does not rain their
kindness
upon
us.

Suffering is a forceful challenge to hope. When we meet suffering with kindness we introduce the possibility of hope. Kindness is transformative; it is the essence of compassionate presence; it is a solace. As clinicians—doctors, nurses, therapists and others—who have an imperative to “fix,” this notion of compassionate presence can be quickly dismissed as pleasantries and impractical. It may also conjure our fears that, in allowing ourselves to become vulnerable, we would jeopardize our ability to function effectively. In fact, it doesn't take any time to connect with this compassion; it's as close as the breath and our willingness to be attentive. And, as for the risks of vulnerability, when we let go of our resistance to it, it can be the source of a deep connection with the persons we accompany.

When we come into contact with a child who is our patient or a parent who suffers with fears and grief, we are presented with an opportunity. Can we open ourselves to the uncertainty of the moment? If we do, and allow ourselves to become vulnerable, we join with another on their path and thus bring them into community—they are not alone. Thus, Eckhart says, “We wither like fields if someone close does not rain their kindness upon us.”

When we meet fear and suffering with kindness it brings healing. Kindness sustains us as we tend others in grief. When we intentionally cultivate kindness and connect it with the experience of our breath, appreciation of the present moment can unfold which, in turn, can lead us to rediscover our innate compassion. Consider this reflection on the words of St. Therese of Lisieux (Simsic, 2003, p. 34):

Therese of Lisieux reassures us that even when we go to sleep at night, we are embraced, like a child, by our loving Parent. We are always in the presence of the Love for which our hearts hunger. We do not have to bring God into our lives as if God were somewhere else . . . We simply need to wake up to the spark of eternal love at the center of our being . . . If we trust in the intimacy of God's loving presence, then we need only pay attention.

The Practice of Compassionate Presence

Stop for a moment and settle.

Let your experience in this moment be just as it is, without making any effort to change it.

Breathe in, gently take a full breath—
this breath is your life in this moment;
pause and appreciate that.

As you breathe out, feel the sensations of the breath as it moves outward,



into the space that surrounds you;
release and let go with the movement of the breath.

To release is to let go of anything that separates you from the present moment of experience – release into this moment.

Repeat this sequence, inviting appreciation with the in-breath,
and relaxation with the out-breath.

As you breathe in -
let the breath fill you with compassionate kindness;
As you breathe out -
extend this kindness outward to others.

Because the breath is present as long as we're alive it's a reliable reminder for connecting with the present moment of experience. However, sometimes we try to make this connection when we're stressed and it seems impossible; ironically these stresses are part and parcel of our work in healthcare. In those moments place more attention on the physical sensation of breathing out, and releasing. Then it's more natural to feel a sense of appreciation when breathing in. While this reflection is not an easy remedy, it won't quickly take away our pain and grief, nor flip a switch to joy, it may help us in moments to reconnect to a deeper integrity. It's a practice; something that becomes familiar and more effective as we use it.

In summary, the spirituality of compassionate presence is a spirituality of attentiveness joined with kindness. When we allow ourselves to be fully present to our experience, and then meet that experience with kindness, some kind of transformation is possible. As Mary Oliver (p. 94) points out in her poem, there seems to be something important, something beautiful, waiting to be rediscovered in this very moment:

I do know how to pay attention, how to fall down
into the grass, how to kneel down in the grass,
how to be idle and blessed, how to stroll through the fields,
which is what I have been doing all day.
Tell me, what else should I have done?
Doesn't everything die at last, and too soon?
Tell me, what is it you plan to do
with your one wild and precious life?

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FAITH COMMUNITIES: A HAND OF MERCY

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Families struggling to manage the many facets of everyday life caring for a child with life-limiting disease or disability need all the help they can get! Local faith communities are a great source for emotional, physical, and spiritual support for these children and their families. This article offers some ideas any faith community may incorporate to lessen this burden for their parishioners and others.

- It is hard for congregations to keep track of patients and families. The lives of these families are often consumed with physician appointments, hospitalizations, or long stretches of time being home bound. For many in the congregation being out of sight is being out of mind. One of the best things a faith community can do to keep the needs of families at the front and able to be addressed is to designate an ambassador in the life of the parish who will remain engaged with the patient and family. These ambassadors can help identify needs that arise which can be addressed by the faith community, as well as serving as advocates for these children and families.
- If your congregation does not have any children with life-limiting conditions don't wait until one comes along. Encourage your faith community to be proactive. Contact a local hospice or pediatric palliative care program and offer help to families and patients. A single faith community can work with a local program to adopt a patient and family to provide a variety of ongoing means of support. Small parishes might consider combining resources to accomplish tasks that they could never do alone. An example is a group of churches that began an ecumenical program to provide a toy closet for patients and their siblings to be distributed by the interdisciplinary team. A similar plan could be devised to provide prepaid gas cards, restaurant gift cards, or lodging vouchers for those who live at a distance from a health care source!
- Another possible outreach for congregations is care baskets. Many times patients and families endure long hospitalizations. Care baskets can provide them some much needed connections with home by reminding them they are not alone. Care baskets can be for patients, caregivers, or both. Some things to think about including are appropriate reading or devotional material, things to help pass the time, neck pillows, snacks, notes or cards, postage, prepaid gas cards, etc...
- Faith communities can offer parents a break from time to time by giving them a night out. Care giving brings a high level of stress upon relationships. As a result, couples or family caregivers are often deprived of opportunities to recreate. Faith communities can do much to alleviate or decrease these stressors, even if it's only an hour or two to relax and get away for dinner or a movie. This will require volunteers who are willing to be trained or prepared for individual patient needs.
- Patients and families may have some financial needs that may not be visible to most people outside the family. Faith communities can offer monetary assistance to help defray these costs or rally the community to provide things like an accessible bathroom or ramp. These forms of assistance have the two-fold benefit of also strengthening bonds within the community.
- Be creative in offering worship experiences beyond the walls of the synagogue or church. The patient and family can often feel isolated and disenfranchised. Consult with the family and you'll



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find ways to overcome this barrier. The gathering of a faith community can make any space a sacred one.

- Faith communities need to invest in access. Spaces for public access are important for faith communities and many times this sacred space is overlooked. Can you get a wheelchair into classrooms, bathrooms, worship areas? Are you prepared to be all inclusive in your offering of sacramental activities as well? The baptistery, altars, and other sacramental areas need to be accessible by all. Seek input from families and consult architects who can help remove these barriers.
- Train appropriate volunteers and staff to be able to provide care that will allow children with life-limiting conditions to participate and provide opportunities for caregiver relief. Your local pediatric palliative care program will gladly help teach faith community members how to provide special care.
- We can't help when we don't know! It is hard to meet a need we are not aware of – so become informed! Even if your faith community doesn't currently have a family with a child with life-limiting conditions, contact your local pediatric palliative care program and let them educate you all in the needs these special people have. Be proactive and progressive, seek out families you might reach out to.

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ASSESSING CULTURAL AND RELIGIOUS DIVERSITY IN PEDIATRIC PALLIATIVE CARE

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As pediatric palliative care continues to become a vital intervention in the medical management of children, it is important to understand the role of making meaning and helping parents articulate their value system as they relate to palliative care.

In recent years research in the arena of religion, spirituality, and culture informs us that patients and their families value inquiry and integration of their spirituality from health care providers, particularly in times of grave illness (Ehman, et.al., 1999). In 2003 Feudtner reported that spiritual care providers believe their institutions provide needed spiritual care services 60% of the time. And yet spiritual needs are also difficult to assess, says Buryaska (2001, p. 119), "...in the same breath with other realities more rooted in the empirical sciences, which currently dominate the practice of medicine."

Quality palliative care depends upon the integration of the spiritual into the overall care plan for children suffering from chronic and terminal illnesses. Parents and patients alike deserve the opportunity to tell the health care team what will be meaningful for them and what values need to be honored in order for medical care to be trustworthy and most effective.

So how does this integration take place? There are at least three tools available to the health care team that facilitate the sharing of cultural and religious concerns in the palliative care process.

The first is a spiritual assessment which should be included in the goals of care process. There are many assessments available, but I recommend the work of Christina M. Puchalski, MD, from George Washington Institute for Spirituality and Health. She developed the FICA system which includes the following:

F--Faith and Belief

"Do you consider yourself spiritual or religious?" or "Do you have spiritual beliefs that help you cope with stress?" If the patient responds "No," the physician might ask, "What gives your life meaning?" Sometimes patients respond with answers such as family, career, or nature.

I--Importance

"What importance does your faith or belief have in your life? Have your beliefs influenced how you take care of yourself in this illness? What role do your beliefs play in regaining your health?"

C--Community

"Are you part of a spiritual or religious community? Is this of support to you and how? Is there a group of people you really love or who are important to you?" Communities such as churches, temples, and mosques, or a group of like-minded friends can serve as strong support systems for some patients.

A--Address in Care

"How would you like me, your healthcare provider, to address these issues in your healthcare?"

The second tool is a framework offered by James Buryaska (2001) that is more appropriately used in the midst of the treatment process than the assessment phase of treatment, as families and patients make



requests of the health care team based on their religious or cultural belief. He says that the team should always “respect the person, critique the claim.”

Buryska suggests asking a series of questions including:

1. Does the request or claim conflict with clinical, legal, or other indications?
2. Does the claim pose a conflict of conscience for those providing care?
3. Is it a positive or negative right that is being claimed?
4. Is the culture or religiosity rooted in community or is it idiosyncratic?
5. Is the person making the request willing to suffer for it? Or expecting that others suffer for it?

The third resource for health care providers is discernment about whether the requests that are made in the midst of serious illness are value generated from spiritual/religious belief systems or situational and emotionally generated. It is important to differentiate in this way so that care providers can most appropriately respond.

A request that comes from religious or cultural value tends to be a request that is held no matter the situation and has been developed over time. In this case, when using Buryska's questions, the care giver is assured about the depth and voracity of the request.

A request that is generated by the situational emotional tends to be related primarily to this case and is not thoughtfully developed. This request has equal value for the patient and family, but the health care team's response is different. Rather than questioning the family or patient, the team would offer space and time to process the feelings related to the request.

This emotional response which is sometimes cloaked in religious or cultural language requires understanding from the health care team and not necessarily action or further explanation. It is important to:

1. Determine which feeling is primary in the request: anger, fear, hurt, or sadness
2. Acknowledge the feeling as a feeling
3. Realize that feelings do not have a “brain” in the sense that feelings are not logical and dealing with them in a logical way may not yield positive results
4. Feelings decrease the ability to hear information

So, in conclusion, honoring the religious and cultural diversity in our patients and families requires that we commit to:

- Assess spiritual needs as part of the Goals of Care discussion
- Discern with the patient and family the source of the spiritual need or request
- Attend to emotional issues that are sometimes embedded in the language of spirituality or religion.

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A HOSPICE CHAPLAIN SUPPORTS A FAMILY

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I first met Mike and his wife Karen, on one of our nurse's regular visits. Their daughter, Kelly, was a tiny little infant, born early, and diagnosed with a chromosomal defect that is fatal to most who have it. Mike and Karen entered our hospice program with clear goals of comfort and only doing "for" their daughter, not "to."

I knew they were well connected to a faith community, but wanted to meet with them and explain how I could supplement their spiritual support.

Once I explained how I could support their religious leader, bring the wisdom and experience of other families, and be a stranger to whom some parents find it easier to speak with at times, Mike was immediately open to my presence and conversation.

We only met face to face twice, and spoke on the phone or through email 3-5 times over the short span of Kelly's life. Yet I asked Mike's permission to write about his perspective because I was struck by how open he was and because I believe his questions and his sharing might benefit others.

It was on that first visit that Mike shared with me a quote from a devotional book that he found helpful. It was a quote by author Joyce Rupp and spoke about why suffering and loss happens. The nurse, Karen, Mike, and I had a great conversation about other beliefs and what brings comfort, or is not helpful.

We talked about how wrestling with beliefs is very common when going through what they are experiencing. He was hungry for perspectives and seeing/hearing how other parents have walked the journey he is walking. He readily took the resources I gave him and followed them up and found some support from them.

He remembers his perspective during that time: "Initially, it was just a sadness that filled me but the sadness went away and was filled with the joy of Kelly. I guess I was more thankful for anything. I initially was really devastated with the news that many Trisomy's don't last very long at all. Every time Kelly beat one of these things, I was just joyful and thanked God for giving me another day. I would say my faith stance was more thankful at this point than anything."

I remember how attentive and intentional he was. He showed me the website they had worked hard on, the video clip of Kelly's baptism, and he spoke about how they were enjoying her, and simultaneously creating memories (pictures, experience, etc.).

Both Mike and Karen also wanted information to help prepare them for what was to come at an unknown moment. Some parents are able and wanting to talk of details such as how she might die, how to keep Kelly pain free through it, how to pick a funeral home, etc. It is very emotional to speak of these things, and some parents believe that to do so can not only distract them from focusing on living life to the fullest, but could also mysteriously make it happen before it otherwise would. Both Mike and Karen did not believe this, and could speak about how, for them, talking and planning for Kelly's death was something they needed to do, and in no way distracted them from spending quality time with her and living with hope that she lives a long time.

Indeed, most of us who work in this field view making such plans and speaking of such things as being a loving and helpful thing to do, both for Kelly and for her parents. It can reduce anxiety if people are



secretly, internally, worried and thinking about it. It can reduce pain and symptoms because certain likely scenarios are voiced and plans are put in place to quickly and thoughtfully respond. Clearly, in Mike and Karen's family, they were able to do so and it in no way distracted them from loving Kelly. While we understand and respect the parents who can't "go there," it is our bias to gently invite parents to look ahead and plan for the "just in case."

Given that they had an involved pastor, and given my goal of supporting and shoring up the family's support system, I next contacted their pastor. Their pastor was grateful for the call, and was open to support. I told him what I had shared with the family what my role would/could be, and then I shared with him details of what conversations he could have with them around the death event. For example: I told him that some parents find it helpful to know they have options at the time when the funeral director comes to their home. They can request that a hearse not be brought, they can request as much time as they want with their daughter's body, and they could request to carry or transport their daughter out to the vehicle or even in their own vehicle (if they have a special permit issued from the funeral director). Their pastor knows Mike and Karen better than I, and can thus discern if and how to offer this information to them. He will be there after I am gone, and I was able to support his knowledge and ability to be with this family in significant ways through this experience.

Mike and I emailed a few resources and comments back and forth a couple of times after this first visit. However, the next time I spoke to either Mike or his pastor was on the day Kelly died. Our nurse received the call and I called the home to express my sympathy and ask if I could help in any way. Mike asked me to call his pastor, which I did.

It was about 2-4 days past Kelly's funeral service, and Mike called me next. I had left a message acknowledging that I knew the memorial service just occurred, offering my prayers and support, and letting them know we would be in touch. I often think of giving families some space (3-6 days) after the funeral before I call to check in and try and schedule a bereavement visit. Mike's message was that he wanted to speak with me. He said,

Karen and I both went back to work on Monday... anyways, give us a call... It's been pretty tough here the last couple of days, it's just been up and down, I talked to Karen last night and we both think that some sort of regular counseling would be good probably... I'm sure you see this all the time.

I called him back that night and we spoke for over an hour.

He shared how his ability to concentrate on work is almost gone, he was surprised by his reactions to things (crying in some places where he didn't expect it, and not in places where he thought he might), and he keeps recalling disturbing images instead of ones he wants to hold in his memory. I simply listened and normalized his responses. I was able to share how other parents have responded and what has helped them. And we set a time for the nurse and me to come back to their house to talk with them, and share resources. Mike needed to get specialized support at this moment and he reached out to me.

Mike recalls his perspective at that time:

After Kelly died, I had a shift. I wasn't able to see her anymore and the thankful feeling for what God had given me subsided and I now was beginning to be angrier. More 'Why us' questions...I didn't understand why it had to be Kelly. As normal life proceeded, I began to get out into the world more and see things that I didn't notice with Kelly because we were always in the hospital or at home under hospice. Kids playing at parks, minivans with little TV's in the back with cartoons on, people pushing strollers, etc. I think my problems with sleeping and concentrating had to mostly do with the intense empty feeling



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I had in my chest. It was like someone cut a huge chunk of me out and I was just empty. I had dreams of my daughter dying. I thought about that a lot. The exact moment when she stopped breathing and I couldn't see her heart move anymore through her delicate skin. At the moment [of death], it was so peaceful but it just haunted me because I knew that was the moment she was gone. I think the thought of her being gone was (and still is) the main driver for the empty feeling in my chest. An emptiness that was constant, overpowering at times, small at other times, but always there.

Mike was able to voice that simply speaking to me reduced his anxiety, and that what we talked about gave him some images, thoughts to hold on to. I felt honored and glad (for his sake, because he sounded so anxious) that he risked reaching out.

At the bereavement visit, we checked in and talked about how they were both doing. We brought many different kinds of books and print material to give them options to choose from, and we discussed all the services and support in the community. They both openly engaged in conversation and shared what each of them were finding that was supportive, and what they struggled with. They took all the resources we brought, and we parted, promising to be in touch with them soon.

I will end with gratitude to Mike for sharing his heart with us, and with his perspective at the time of our last visit with them in their home:

I was much better at this point. Even 2 weeks from the first point and just dealing with the issues as they came up helped a ton.

My questions have shifted more during this time to finding out what heaven is like. I know, without a doubt, that Kelly is in heaven. I am back to being thankful for God's gift of baptism and for giving me 43 days with Kelly. My wife can use the fact that Kelly is in heaven to get over a great deal of her grief but I am having trouble with it. It's like the hole inside me is so big and, though I know she is in heaven and is without pain, it isn't enough to fill the hole all the way. It just makes it smaller. It also seems like I am back on the free will train of thought and not as mad at God any more. I know He didn't make this happen to me. He doesn't want to make me go through this pain, it just happened. I still have my bouts of questions and resultant anger but I don't stay pissed off for so long. I also know that things are never going to be the same either... I miss her like crazy....

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ONE CARE PROVIDER'S JOURNEY IN PEDIATRIC PALLIATIVE CARE: FROM NURSING TO MINISTRY TO PROGRAM DIRECTOR

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When anyone looks back to see where something began, it is like looking at a large tapestry for particular continuous threads. Pediatrics is one such thread in my tapestry and another is working with life-threatening children, teens, and young adults and their families. These two threads began very early as a student nurse, and kept recurring as I moved through a career that now stretches over several decades. It is not a calling that one seeks—it finds you.

The focused part of this journey began in 1978 at the Center for Attitudinal Healing in Marin County. At that time, the Center had a weekly support group of children with life-threatening illnesses; and at the same time and place, a group for parents and one for siblings. Very quickly, a young adult group for people from about 15-16 to 25 was added. I became the facilitator in 1980. During my five years at the Center, I worked with many children and teens who died at home—their parents often doing all the care without hospice team guidance.

During those years, I observed something I still believe to be true. The best place for a child to die—assuming there is the support and desire of the parents—is at home.

My experience at the Center led to an invitation to become the program director of the second pediatric home hospice care program in California, PediatriCare, in early 1983. Although an independent non-profit, we had an office and the support of Children's Hospital, Oakland. Our patients and families came from all the major pediatric hospitals in the greater Bay Area—the territory became literally hundreds of square miles.

In 1983, the concept of children dying at home was still “new.” Ida Martinson's research had been published establishing the advantages of children being at home surrounded by their families at the time of death. Belinda Martin at Los Angeles Children's Hospital had begun the first program in the state and was a valuable resource for us. But in spite of the research, there was plenty of resistance from all corners. Change always results in resistance, and home care for dying children was no exception.

The greatest challenge was with nurses. Very few adult home and hospice care nurses had ever cared for children. The structure for PediatriCare was that we would coordinate care, but the day-to-day hands-on care was to be delivered by nurses in hospice agencies sprinkled all over the greater bay area. To accomplish this goal, I developed a curriculum and taught pediatric palliative care to nurses in hospice care agencies and to nurses in agencies providing shift care in the home in all the counties surrounding San Francisco Bay and some to the north, south, and east. Almost 200 children received care through the program. Because of the demands of care at home, I gave direct care as needed with numerous families when their children were actively dying. We also provided bereavement support.

Some aspects about pediatric palliative care were easier then than now. Travel was easier as traffic was far less congested. California Children's Services and other funding agencies were generous as all of us were charting new ground. Hospice, in general, was less regulated and more willing to take risks that might not happen today.



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I remember a child who wanted to die at home in her garden. She was very sick with end-stage leukemia receiving fluids and pain medications through a Broviac line. There was no immediate nursing care in west Marin County. The family had little in the way of resources, but they were part of a close knit community and deeply spiritual. The day after she let us know where she wanted to be, a parade of cars left the hospital—the child in the back of an elderly station wagon with her parents, followed by neighbors with all her supplies and stuff, and finally my own car. Sitting in her garden before sundown, she died two or so hours later.

Pediatric hospice care is different because it involves the care of the whole family, and sometimes, an entire community. A home visit with the child and his or her parents and siblings can turn into an entire day, including a drive over to the local school to talk to the child's classmates or hanging out at a local pizza joint with a teenager's friends processing their anticipated losses. Funding for the intensity and open-ended quality of pediatric palliative care remains challenging.

Experiences with these young people and their families always included spiritual care. For example: What is heaven?" "Where is heaven?" "Why doesn't God make me better?" "Will dying hurt?" "Why is God taking away everything I care about?" The deeper my engagement with families, the more my spirituality was challenged. As important, I found that the young people and the parents I served were amazing spiritual teachers. I remember sitting with an eight year old while his mother went out to shop for dinner. He said to me: "Put the CD with the flutes on and sit in the rocker next to me while I go to heaven. It won't hurt her so much if I go now." He was right. On a bereavement visit, a five-year-old sibling wandered into the living room and casually said to his mother: "I have been playing with Vinnie. He said to tell you he is happy." A fourteen year old told his mother and me that dying was a "triumph of the spirit."

Faith plays a major role in a family's capacity to cope with the experience of caring for a dying child. More than a particular religious path or one's spirituality, faith is expressed in many ways. Sometimes people place their hope in God, or find meaning in Scripture, or in family, natural beauty, or cultural tradition. I have observed that families who share their faith find the strength to persevere through the experience and challenges of the dying and the death of a beloved child.

I never planned on going to seminary, but gradually nothing else seemed as "right." Attending seminary did not provide answers to the hard questions, but it did give me context and a new path. I never planned on ordination either, but that became part of this new path. I left pediatric hospice care a few months before graduation. Originally, I thought I would work as a hospital chaplain, but I ended up in teaching and parish ministry that included children and youth; and, during the early and mid nineties, I facilitated groups of persons with AIDS.

Over the years I kept in touch with John Golenski, the executive director and co founder of PediatriCare. After GeorgeMark Children's House (GMCH) opened and John became the second executive director, he called me to ask if I was open to working at GeorgeMark as a chaplain if the need should ever arise. The time was not right, but once I toured GMCH and had time with Dr. Beach (one of the principal physicians in PediatriCare and now the medical director of GMCH), I wondered if those continuous threads of pediatrics and working with life-threatened children were re-emerging. I retired from parish ministry in 2005, and three weeks later, John was literally on my doorstep asking me to come to GeorgeMark as program director.

I said yes largely because it seemed like a full circle. And there was Johnny.

I met Johnny and his family at Children's Hospital in Oakland in the late 80's. Johnny was 12 and had an incurable non-Hodgkin's lymphoma. He lived with his mother and two siblings in a comfortable suburban apartment. Johnny's father had died suddenly two years earlier. In meetings with his mother, I recognized



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the symptoms of depression and acute grief. Medications and a support group had helped her, but she admitted difficulty keeping up with the demands of Johnny's illness and caring for the other children.

Leaving the hospital was all Johnny wanted—he knew his diagnosis and prognosis. His mother agreed to his “dying wish.” I made several visits and all seemed to be going fairly well (with a local agency's assistance)—although pain management was an ongoing challenge.

During my last visit, I noticed that Johnny had a bandage on his abdomen, and the wound looked like an ugly second degree burn. At first, Johnny said he did not know what happened, but then he admitted to me that his mother had accidentally poured hot coffee on him. When I questioned his mother, she said she tripped. Later, she admitted that she could not cope any more. When I told Johnny he had to go back to the hospital, he cried and asked me, “Aren't there any foster homes for dying children?”

I have never forgotten Johnny. If GMCH had been open then, his mother and sisters would have had a close loving experience in a home-like setting with all the family support they needed. Johnny's mother was not an unloving mother. On the contrary, she adored him but she was unable to cope at home. What their family needed was the second-best place for a child to die—GeorgeMark Children's House.

I have been given many gifts of love and faith in my life. To be working at GeorgeMark is one of those gifts, and is a daily reminder of the capacity for healing and strength within the human soul and spirit. The human spirit is far stronger and greater than we can imagine even in the pain of loss. I have seen it in the eyes of dying babies, felt it in blind, non-verbal children, and heard it in teenagers wise beyond their years. It is nothing less than a privilege to be working with young people and their families in pediatric palliative care.

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TRANSFORMATION AND TRANSCENDENCE IN SELECTED EXAMPLES OF CHILDREN'S LITERATURE

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Issues associated with transformation and transcendence often arise in discussions of religious, spiritual, or existential matters. Here are nine examples of literature written for children that address these subjects. Some of these books describe a transformation from one life form to another that occurs at the moment of death; others refer more directly to heaven or some other mode of an afterlife. Adults can give these books 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.

The Cherry Blossom Tree: A Grandfather Talks about Life and Death (J. Godfrey; Minneapolis: Augsburg Fortress, 1996) is a story about five-year-old Harriet and her grandfather who plant a cherry tree that is covered with pink blossoms each year on his birthday. One year, when they find the tree has fallen down, Grandpa says, "It was very, very old, and time for it to die." He explains, "Everything that is born has to die sometime. . . . And that makes us sad. But death is a new beginning, like waking up after a long sleep." According to Grandpa, everyone who loves God can go and be with Him when they die in a new and different place called heaven. Harriet and Grandpa then plant a cherry pit, secure in the knowledge that it will grow into a new and beautiful tree.

The Magic Moth (V. Lee; NY: Seabury, 1972) tells the story of a six-year-old boy who is trying to make sense of what is happening to his 10-year-old sister who is dying of an incurable heart disease. The book introduces two examples: one of seeds that need to dry out and break open before they can give birth to new life; another of a brilliant red and green caterpillar in its cocoon and its transformation into a lovely moth to reinforce the minister's conviction that "life never ends—it just changes" (p. 45).

Mama's Going to Heaven Soon (K. M. Copeland; Minneapolis: Augsburg Fortress, 2005) employs vivid colors and minimal text to describe for young readers the reactions of two children when their Mama becomes ill. Daddy tells the children that Mama will soon go to heaven to live with God and the angels. He is careful to add that although Mama will be gone forever she will always love her children. Remembering her love and talking about feelings with Daddy can help.

On the Wings of a Butterfly (M. Maple; Seattle: Parenting Press, 1992) tells a story about Lisa, a child dying of cancer, and Sonya, her caterpillar friend, who share insights and experiences as Lisa approaches her death and Sonya prepares for her transformation into a Monarch butterfly.

Serafina's Silver Web (I. Evenson; Richmond, VA: Noah's Children, Inc. [6954 Forest Hill Avenue, Richmond, VA 23225; tel. 804-327-8417; www.noahschildren.org], 1999) is a story about a dying boy who develops a special relationship with a spider. Serafina, the spider, takes Peter on many magical adventures, including a trip around the world. When Peter tells Serafina that he is frightened of death, she says that he need not be because, "death is a journey. There is nothing for you to be afraid of. . . . You simply leave your body behind and continue your life without it" (p. 30). One day, Serafina tells Peter "my time here on earth is up. I have fulfilled my purpose and must now return to where I came from" (p. 33). She leaves her old body behind and departs Peter's world, but soon they are reunited as spirits on a new journey.



Water Bugs and Dragonflies (D. Stickney; NY: Pilgrim Press, 1982) tackles the following question: If there really is a transformation in death to another mode of living, why is it that we know so little about the nature of that other life? In this story, a colony of water bugs notices that from time to time one of their group climbs up the stem of a plant, crosses a boundary at the surface of the water, and never returns. They each pledge that the next one among them who makes this journey will come back to tell the group what happens. In fact, the next water bug discovers that this departure leads to a transformation into a dragonfly. Living above the water is a new and exciting experience, but the dragonfly discovers it is now impossible to penetrate the surface of the water and go back to the underwater colony. The lesson is that each individual must experience his or her own transformation in order to appreciate what it entails.

What's Heaven? (M. Shriver; NY: Golden Books, 1999) is based on a discussion between the author and her 5- and 6-year-old daughters when their great-grandmother, Rose Fitzgerald Kennedy, died. The book suggests that heaven is a place without hurts where your soul and all the things we love best about a person go when you die.

Where Is Grandpa? (T. A. Barron; NY: Philomel Books, 2000) is a story about family members who tell a young boy that his Grandpa who has died is now in *heaven* and that "heaven is any place where people who love each other have shared some time together." The boy is comforted by the thought that Grandpa is way off in the Never Summer range of the Rockies that they used to look at together "as far as we can possibly see" from the tree house they built together.

Where the Balloons Go (P. Coleman; Omaha, NE: Centering Corporation, 1996) uses the metaphor of balloons to talk about life after death. When Corey asks where balloons go as they fly up into the sky, Grandma suggests that perhaps their destination is a lovely Balloon Forest. Later, after Grandma becomes sick and dies, Corey wishes that his balloons could carry him up to the Balloon Forest to see Grandma, but settles for attaching a message of his love to a balloon and releasing it.

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 which 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 using it as a springboard to work out and share their own ideas and beliefs 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 roles 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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THE *MY WISHES* DOCUMENT

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It is never easy when someone we love becomes seriously ill, and it is even more difficult when that person is a young child. There is understandably an emphasis on getting the most accurate diagnosis and obtaining the best medical care possible. Even if the child is not yet old enough to make medical decisions, it is important to talk to the child about what they want, what makes them feel safe and comfortable, and what they want their parents, doctors, and nurses to know. These can be difficult topics to broach.

A new document called *My Wishes* makes these difficult conversations easier. Based on the popular *Five Wishes* advance directive, which is used by more than 11 million adults to express their healthcare preferences, *My Wishes* helps identify what is important to children who are facing a serious illness. *My Wishes* and *Five Wishes* are both offered by Aging with Dignity, a national nonprofit organization with a mission to safeguard the human dignity of those who are most vulnerable, especially those who are seriously ill.

"Being the parent of young children myself, I can understand the sensitive nature of these conversations," says Paul Malley, president of Aging with Dignity. "*My Wishes* puts the discussion in terms that are meaningful and understandable for the children – and it provides a guide for parents, caregivers, and health providers to address these important issues without starting from scratch."

My Wishes is a simple booklet developed by child life professionals that helps children express their wishes in their own words. Laid out in a colorful document with plenty of space on each page for children to draw or write stories, *My Wishes* includes the following examples:

Wish #1: My Wish for how I want people to treat me

"I wish to be cared for with kindness and cheerfulness; I wish to have my hand held and to be talked to whenever possible." Children are given space to affirm these and other statements about the type of compassionate care they would like to receive. They are given the opportunity to draw pictures of their favorite things that they may want to have with them.

Wish #2: My Wish for how comfortable I want to be

"I do not want to be in pain; These things make me feel good; These are some things that I do not like." Wish #2 is an important tool in helping understand children's approach to pain management. Many people have different approaches to pain management, especially when they may become tired as a result.

Wish #3: My Wish for what I want my loved ones to know

"I wish to have my family and friends know that I love them; I wish for all of my family members to be nice to each other." *My Wishes* deals with more than medical issues—it helps to address important emotional issues, including love and forgiveness.

Wish #4: What I want my doctors and nurses to know

"I want you to call me by my name or nickname; I know I need time to rest and sleep, but I also want to have time to play." Wish #4 helps children explain to their health care provider how they want to be addressed, how they want to be talked to about medical



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issues, and assert that they would like measures taken to respect their dignity and privacy.

My Wishes speaks to children in language that is easy to understand, saying that “there are many things in life that are out of your hands. *My Wishes* gives you a way to control something very important - how you are treated if you are very sick. It is easy to complete, and helps you say exactly what you want.”

Amy L. Blais, Pediatric Hospitalist at Central DuPage Hospital in Winfield, IL, offers an example of how *My Wishes* has helped children, parents, and health care providers communicate:

“One night in the PICU the condition of one of our pediatric patients became acutely worse. A copy of *My Wishes* was available on the unit. I spoke with the parents outside of our patient's room and then brought the booklet into the room. As a group, the patient, his parents and I worked through the issues. Having a chronic, potentially fatal illness, my patient had thought about many of the issues before and had strong opinions as to what he wanted.

With the help of the *My Wishes* booklet, I was able to answer his questions and address his concerns. Prior to that night, he was not aware that they could become part of the medical record and be heeded by the medical team. It was a comfort to his family and the staff involved that his wishes were followed.”

My Wishes can be given to a child by a parent, a caregiver, or a healthcare provider. The time to introduce *My Wishes* can be after a new diagnosis or a change in condition, or as a preparation for an upcoming hospital procedure. Any time when important medical decisions are being made in the life of a seriously ill child, *My Wishes* can help make these conversations a little easier.

To get copies of *My Wishes*, visit www.agingwithdignity.org or call (888) 594-7437.

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MY COMIX

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My Comix is an interactive computer game for children and teens with life threatening illnesses. We are accepting names of organizations interested in offering the online game free of charge to their families as part of a one-year pilot program. The online community and interactive game will be available Fall 2008.

Visit mycomix.org to see a demo and sign up for more information.

The game gives adolescent/young children a way to share things that are very hard to talk about using comic book characters. It offers family members and healthcare professionals an easier way to initiate conversation around disease-related topics, especially unspoken fears.

In the game, children and their families can combine super heroes and other comic book characters, personal writing and graphics to make their own interactive **Comic Book and Super Hero Postcard**. Using 2-D interactive animation, comic book characters guide kids to choose word bubbles, objects, scenarios and backgrounds to tell their story. The Super Hero Postcard allows kids to identify themselves as a Super Hero, and email their favorite character to friends in 14 languages.

A prototype of the game is being tested at the George Mark Children's House through a grant from the Haas Foundation. There has been overwhelming response by the children who have participated in **My Comix** to make the game part of an online community to provide emotional support and a way to share their comic books with other children, friends and families. The online community makes the game a larger, more accessible creativity tool reaching diverse cultures.

With overwhelming interest for the game, it has the potential to reach over 1 million families nation-wide through the online community.

Program Design: The project is based on significant evidence identifying online games and social networking platforms as a successful model to reach our targeted audience. Mediamark Research Inc. shows more than half of American 6-to-11-year-olds have gone online in the past 30 days (April, 2007).

Our goals are: (1) to identify how adolescent/young adults use this game to create support, share ideas and communicate with family, friends and others; and (2) To understand better how online games can be used more effectively to provide emotional support for this community.

For a demo, and additional information, please visit
<http://mycomix.org>.

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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 of This Newsletter. 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 spirituality. In the immediate future, we are considering an issue on **volunteers and professional specialists who contribute to the work of interdisciplinary teams in PPC**. There are many 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) and the opportunity to look at their work will be valuable. 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. 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. To download the conference brochure and/or register online, visit www.nhpc.org/conferences.

3. Support Partnering for Children/Wear a Bracelet. Partnering for Children (www.partneringforchildren.org) is a national awareness campaign that was launched November 2007 at NHPCO's 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](http://www.childrenshospiceandpalliativecare.org) 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 www.partneringforchildren.org.

4. 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) and ChiPPS. Members may download this issue in PDF from the NHPCO Web site at www.nhpc.org/newslines.

5. NHPCO and ChiPPS Pediatric Listserv. NHPCO and ChiPPS are pleased to announce a special pediatric listserv for NCHPP or eNCHPP members who provide services for children with life-threatening conditions and their families. [Read more](#) about the listserv and eligibility requirements to participate. [Join the Pediatric Listserv](#).

6. Calendar of Events. As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, www.nhpc.org/pediatrics.



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work.

If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to CHIPPS2@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the **Communications Preferences** tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800/646-6460.

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

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