A Special Message from Don

As we go to press with this issue of NewsLine/Insights, we have confirmed that there will be a six-month delay in the implementation of CR5567 (i.e., the new requirement asking for more information on hospice claim forms that was proposed by CMS). The original deadline for compliance—January 1, 2008—has now been extended to July 1, 2008, providing a more realistic time frame for providers to meet this requirement.

While some staff and volunteers might not be focused on this topic, the additional six months represents a significant achievement on behalf of NHPCO’s senior leadership and its regulatory and public policy teams. Additionally, I want to thank those members who offered us feedback on CR5567—particularly those who responded to our call to write CMS with their concerns.

Although we have been able to facilitate a delay in implementation, this is by no means an end to CMS’s desire to collect more data on hospice care. NHPCO will be working with its various committees and the membership as well as with CMS, the Fiscal Intermediaries, and MedPAC to develop a comprehensive process to advance a tool that is a useful gauge of the care that we provide.

While there have been many achievements over the course of 2007, it’s nice to end the year with a special achievement like this. As the year comes to a close, I hope each of you will take time to reflect on your accomplishments—both personal and professional.

On behalf of NHPCO, my best to you and your family during the holiday season. I look forward to our continued work in the year ahead.

J. Donald Schumacher
President/CEO
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**About the Photos in This Issue:** On our front cover and throughout this issue, we are proud to feature many of the photographs received for NHPCO’s annual Photography, Film, and Writing Contest—which has been held for members since 2003. Also, be sure to turn to page 50 for the winners of this year’s competition.
Exploring the Special Needs of Children and Their Families

Caring for children and supporting families during a life-limiting illness is probably one of our toughest challenges. It calls for special expertise. It calls for special funding. And, quite frankly, it requires courage—because losing a child is also one of our greatest fears.

This issue explores some of the special ways we can help improve the quality and delivery of pediatric palliative care. In Sections One and Two, interdisciplinary team members discuss how to help children cope with the emotional and spiritual aspects of their illness, how best to support parents through the process, and important considerations when managing a child’s pain. Our concluding sections take a closer look at some programs which are now meeting this important need, plus the new national campaign—sponsored by NHPCO and the Children’s Hospice and Palliative Care Coalition—to help other programs expand access.

You will also hear from parents themselves—who give voice to the challenges and benefits that come with caring for children. In the essay on page 18, we enter the world of parent Elizabeth Uppman and share her exasperation and pain.... “I realize that I’ve been hoping the nurse and the social worker would take over for me,” she writes. “I’ve been hoping this would start being somebody else’s life.” And in the essay on page 25, parent Lisa Burman reminds us of the good we can bring to a bad situation.... “As parents we had to care for a child with unique needs, and maintain a sense of normalcy for our five other children. Palliative care and hospice made our goal reachable.”

While all programs may not be equipped to provide pediatric palliative care, every program can help ensure that children in their communities receive quality care through appropriate referrals. Our hope is that this issue helps remind you of the special needs of children and the important role you play in meeting those needs.

NHPCO extends special thanks to the National Council of Hospice and Palliative Professionals and to the Children’s Project on Palliative/Hospice Services for their expertise and collaborative work on this issue.
Creating art is the natural language of children. Working in images can provide a means of bringing forth feelings and ideas through pictures, metaphors and themes in a natural, safe and non-confrontational way. Children within the pediatric hospice setting, whether patient or sibling, will generally gravitate toward the opportunity to express themselves through art.

There are many ways that art therapy is valuable and effective with the pediatric population—to say goodbye, to express hopes or fears, to assist cognitive development, to offer meaningful activity, pleasure, success or relaxation, to communicate with those around them, and as a way to understand themselves and what is happening more clearly.

Sometimes children will answer an adult’s questions about what they are thinking or feeling through their art. For example, when entering the home of a 6-year-old child who was dying, her family quietly told the art therapist that they didn’t think their child knew that she was dying and they didn’t want the art therapist to bring it up. So the art therapist simply offered the opportunity for this patient to paint or draw. The child, Angelique, who was very ill and was lying in her hospital bed in the dining room, responded by asking the therapist to help her draw an angel. So working hand-over-hand, together they drew an angel with a pink marker. When the art therapist asked the name of the angel, she said “Angelique” and wrote her name by the angel. This drawing was hung over the bed where she could see it, as could all the family members when they sat with her. In this way, Angelique was able to assure her family that she knew that she would be an angel without saying a word. Angelique died just days later. The family said this simple drawing helped everyone know that she would be all right.

Art therapy can also bring a family together by working on a project, like making stepping stones with their handprints, or working on a quilt where the child draws pictures that are transferred to fabric. Sometimes art therapy can help a child or adult relax and “feel normal” for a while. At other times, art tasks can positively affirm a patient’s abilities. Five-year-old Sally used to cut pictures apart into slivers of paper. She loved this activity. So we found the most interesting and beautiful pictures in themes of her choice, like kittens or apples, for her to cut. Wherever she was, there would always be little cuttings lying on the floor around her wheelchair. One day we started to weave these pieces together and, eventually, we had a wonderful weaving of all sorts of colors. We framed it and she chose where to hang it in Hospice House (the residential facility of Hospice of the Western Reserve) where she was a patient. Every day after that when she came to the art studio, she would sit where she could see her weaving and watch to see if anyone would look at it (which often happened). This acknowledgment of her art was very affirming for her. For Sally, this...
Sometimes children will answer an adult’s questions about what they are thinking or feeling through their art.

activity was relaxing and soothing with its comfortable repetition. And she also experienced a sense of control, mastery and success while doing this task.

Making art can also offer creative ways of dealing with death, loss and grief. DJ, a 7-year-old boy with terminal cancer who was living at Hospice House, was very affected by the death of another child, Anna, who had just died there. However, DJ refused to talk about it.

Soon after, DJ met individually with the art therapist. After making some images spontaneously, the art therapist asked him to talk about the last time he had seen Anna. He looked down as he described going to her room shortly before she died and asking her to play. “She was mean to me and told me she didn’t want to play with me...she called me a name,” he explained. The art therapist validated his experience, stating, “It sounds like the last time you saw her you had a bad goodbye.” DJ quickly agreed. The art therapist then asked DJ to make a picture of a “good goodbye.” DJ started to work right away, making a “hand-waving goodbye and a blue heart.” Then a poem was created as the art therapist wrote his words on the picture: “Anna, I came to play, but you were gone, so I’m waving goodbye. My heart is blue. DJ.”

DJ decided he wanted this painting to be placed in Anna’s casket with her. The art therapist took this transitional object, his painting of “a good goodbye,” to Anna’s funeral for him.

When a person dies, or is dying, art therapy and art making can be a meaningful way to assist children and their loved ones to process, grieve, and adapt to the situation. This work can assist them to accept and better understand themselves and the world around them. It can help everyone to have a good goodbye.

Barbara Trauger-Querry has worked in a variety of capacities during her 23 years of service at Hospice of the Western Reserve, in Cleveland, Ohio—including volunteer management and training, bereavement counseling, and spiritual care. After earning her master’s degree in art therapy, she developed the Art Therapy Program for HWR in 1994, where she continues to work as an art therapist. She also serves as a member of NCHPP’s Allied Therapist Steering Committee.
In July 2001, my journey with pediatric hospice began with children and their families who found themselves struggling with the realities of living with life-limiting illness. The pediatric homecare team was just being formed as I came on staff at the Hospice and Palliative Care Center in Winston-Salem, North Carolina. As we built the program from the ground up, I began to hear from our patients and families about the recurring nightmares they were experiencing, especially as their disease process intensified. This reminded me of the stories I heard from pediatric patients and families during my clinical residency at Wake Forest Baptist Medical Center. One common theme emerged as I went from family to family, hearing the stories of their dreams. For dying children and their families, “giants and monsters” continually and regularly reared their heads in dreamtime.

From a Jungian perspective, dreams move us toward inner balance and have the purpose of guiding us toward health and healing as they access the collective unconscious and the archetypes that give us entry into the spiritual realm. I heard in these dreams the archetypal journey of the hero who encountered overwhelming danger and annihilating forces in the form of giants and monsters, in the struggle to find the mystical resource or aid that would vanquish the foe, against insurmountable odds. J. E. Cirlot, in his Dictionary of Symbols, postulated that there are symbols accessed in dreams so powerful “they constitute the deepest strata of spiritual geology...until they erupt in the shapes of giants and monsters.” These archetypal images, found in our most ancient myths and sagas, stand at the core of primitive creation narratives and are even reflected in early cave drawings. The Gilgamesh Epic (2000 BCE) has the giant Humbaba; Beowulf (700 CE) has the monster Grendel; and races of giants are called the Risar in Norse myths, Daityas in India, and Nephilim by ancient Hebrews. Within these ancient myths and sagas, the archetype of the hero always held a magical/mystical weapon capable of vanquishing the giant or monster. From the deep strata of the collective unconscious, these mystical weapons are the “symbolic antithesis to monsters.”

The task before me as a clinician became, “how do I develop a technique utilizing guided spiritual play that will access those mystical tools for children facing giants and monsters in their dreams?” As I developed and practiced this technique, I found that the giants and monsters disappeared, or were even transformed, as dreams were processed through guided spiritual play that made dream images accessible for children. As these dreams were processed, they often presaged the coming of powerful numinous dreams that served as spiritual signposts to sentinel events for children, siblings and parents; and later as spiritual touchstones for grieving families.

### Dreamwork Technique

#### The Journey In
Using active imagination principles, the chaplain, child, and other family members (most often siblings) re-enter the dream with carefully crafted play to engage the giant or monster in a waking state to help in the processing of the nightmare images.

Chairs are arranged like an airplane or bus, with chaplain and child in the front two seats. Toys are used to simulate controls for maneuvering the craft (i.e. steering wheel, knobs, buttons). “Safe place protocol” (created by the child) is rehearsed, accompanied by the motions and sounds of
As I developed... this technique, I found the giants and monsters disappeared, or were even transformed, as dreams were processed through guided spiritual play....

dashing to the safe place, with everyone practicing in unison (i.e. stomping to simulate running, hand-over-hand motion to simulate climbing)—a scripted intervention the child can choose to access at any time. The child is given three “safe place” buttons, to opt out of the dream play at any point.

The Guide
The chaplain or other clinician sensitized to children’s developmental stages, with knowledge of core spiritual tasks, directs the intervention.

The Power Tools
The chaplain asks the child, “what do you need to hold in your hand to keep you safe when the monster/giant appears?” The child chooses a “power tool” that will keep him/her safe (e.g., sword, flashlight, rope, lantern, parachute, wings).

The Vehicle
An “impenetrable bubble” or “sphere-shaped shield” that can be seen through very clearly, can float in the air, go under the sea, and move through time, is employed. The chaplain uses “ritual” or “ceremony,” complete with sound effects, to "grow" the bubble or "raise" the shield around everyone journeying in the vehicle.

The Story
The child tells the "story" of the dream within the safety of the bubble/shield. Armed with the “power tool,” the child re-creates the dream. The child and chaplain engage the senses by making the sounds of the journey—stomping feet while walking down a path, fingertips snapping for rain, etc. The guide helps the child describe the surroundings—"seeing" the colors, plants, and animals; "smelling" the air for scents; shading the eyes from the sun to see at a distance. The child is encouraged to actively use the “controls” of the vehicle to maneuver around obstacles.

The Nightmare—Changing the Outcome
When the monster/giant appears, the guide asks what the child wishes to do. Then we “play” the intervention.

Example:

- The dream of a child, who is 7-years-old, has cancer, and has about four months to live: “It was dark outside and I was running to get to my house. I could see the lights on and I kept on running but I couldn’t get home. There was a monster chasing me, growling like a tiger. I try to run hard, but I can’t get home. The monster is going to eat me.”

continued on next page
This child chooses a “sword made of light” as her power tool.

The guide asks to talk with the monster, and the child answers for the monster:
Q: "Why are you here?"
A: “To eat her up”
Q: “Why do you want to eat her up?”
A: “I’m hungry”

The guide asks the child to suggest something else for the monster to eat. Then the guide instructs the monster that it could not return to scare again. The child shows the power tool to the monster, saying it would keep her safe. The monster stays outside the impenetrable bubble/shield at all times. The guide assures the child the power tool is always with her; if she calls for the tool, it will appear.

The Pathway Out
The way out engages the same sights, sounds, and smells as the narrative of the journey in. The same ritual/ceremony is used to dissolve the bubble/shield. The chaplain debriefs the child (“What was the best part, the scariest part?”) and then they celebrate (give “high 5s”; do a “victory dance”). This technique can also be used (with variation in power tools and interventions) to help provide the framework for the numinous dream that often appears before death. These are dreams charged with profound spiritual energy. Providing a creative context for engaging the numinous aids the process of making meaning, finding hope, and feeling safe. Families may begin to recall and retell stories of numinous dreams in the past, normalizing this process in the family story. It is a framework that allows families to see the child’s story merging with their sacred story in a way that brings hope and healing.

Beverly Isley-Landreth is a chaplain and bereavement coordinator for Hospice and Palliative CareCenter in Winston-Salem, North Carolina. She served as pediatric chaplain for the Pediatric Homecare Team of The Carousel Center from July 2001 to March 2006.

References:
2  Ibid.

National Children’s Memorial Day:
December 9, 2007

In 1997, the United States Congress declared the second Sunday in December as National Children’s Memorial Day—a time to remember children who had died too soon. Initiated by The Compassionate Friends and other groups dedicated to working with bereaved families, National Children’s Memorial Day has become a tribute to the lives of children. If you have not done so already, add this important date to the remembrances on your program calendar as one more way to raise awareness of the needs of children and their families.
Soccer player, bear collector, friend, lover of things Irish, cellist, Japanese language student, sister, and daughter—Daron. She was 16-years-old when she was admitted to the Stepping Stones Pediatric Program of Providence Hospice of Seattle. For nine months, our interdisciplinary hospice team journeyed with Daron and her family, gathering pictures and stories from her mom Pam, siblings, friends, and medical staff. We came to know Daron as a young woman with great aspirations and courage—she truly lived into her death. The brain tumor she lived with suffocated language, depleted energy, stole memory—but Daron adapted, Daron lived.

Making connections with patients and families who are experiencing rapid change and deep grief is a challenge. Given these circumstances, the hospice team applied themselves quickly to learn about Daron’s medications and comfort measures. Most importantly, the team inquired about the simplest and most important elements of daily living: Pam and Daron’s preferred lattes, the names of the family cats, Daron’s favorite U2 song, the most recently released “Muffy” bear in the collection, and the Bath and Body Works lotion scent she most enjoyed.

The team also took risks, offering various and even unusual approaches to emotional and spiritual comfort, including different forms of light touch therapy. Daron quickly responded with a nod to offers of a Reiki practitioner. She had a deep knowing of her needs. It seems that Reiki allowed her to move experiences that could not be expressed by words. In Daron’s last meeting with her psychologist, this practitioner reported, “The only word she said was Reiki. She’s tired of trips to the hospital.” While Daron expressed herself in poetry and writing prior to her illness (two of her poems appear on page 14), the hospice team did not share a verbal relationship with Daron. Quiet time, sharing Reiki, and listening to Pam’s stories allowed the team to appreciate Daron’s essence. Daron adapted; the team adapted. Daron lived.

Still, Pam was watching her creative, athletic, teenage daughter become physically weaker and more confused, and she was open to having someone with whom she could process these changes. A chaplain/bereavement support counselor was welcomed into Daron’s home, specifically to be a resource for Pam. Several months before Daron’s death, Pam initiated a conversation with the counselor about time of death and funeral plans. This topic is especially sensitive in end-of-life care with children, and the team approach is to allow the family to lead, even if plans need to be made after the death. Some families say that to make plans for death is to give up on hope. Pam, when given the opportunity to explore her hopes for memorial/funeral plans, discovered
that handing Daron’s body over to a funeral home when she died made her uncomfortable. This fear of transition of the body after death follows closely with the experience of other parents. “When do you just hand your child over to a stranger?” she asked. She discovered she was opposed to embalming. Her role as protector fiercely rose up. Pam invited the team to explore options for Daron’s support and comfort in death. Pam adapted, the team adapted.

At the time, Pam had no knowledge of family-directed funerals, but the chaplain and the pediatric care team had been aware of this service in the community through other families who had chosen this option. Pam was able to voice her concern and hopes, ultimately discovering an alternative approach. The hospice MSW introduced Pam to Char, a death midwife and funeral director who supports families in the family-directed funeral process. Char gently walked Pam through the steps of having a loved one’s body prepared and viewed at home. She assured Pam that she would be available to support her in this process, but that Pam and her family had the personal ability to do much of the work. Pam asked a lot of questions and felt some relief that this was a route she could take. Once Pam could visualize what it would be like to have Daron’s body prepared, viewed and placed in a simple casket in their apartment, some of her tension and fear was released. There was a goal, a hands-on gift one might say, that this mother could give her child at the end. Pam and Daron adapted. Pam and Daron lived.

On the afternoon that Daron died, she was surrounded by many family members, hospice team members, friends and her beloved animals. She died peacefully. Her body remained at home for two days with the use of dry ice. Daron was bathed and dressed by Pam and Char, and her sisters. Daron’s makeup was applied by her oldest sister, Tara. Due to winter storm conditions, Tara had been waiting for delayed flights and was not present at the time of Daron’s death. Tara reports that the experience of time alone with Daron to apply her makeup and prepare her for viewing was exceedingly profound and helpful in her grief experience. Loved ones gathered in the home, then at the gravesite, then in the church for a memorial service. Daron is buried in a small cemetery situated next to the high school she would have attended. Daron’s memory lives on.

Life continues. Over the next year, Pam’s third grandchild is born. Then, a co-worker is diagnosed
with cancer and Pam wonders how to be supportive, and if she has the strength to be there for her. Pam also listens to her other three children and their needs in talking about their sister. She realizes that sometimes they don’t talk for fear of making her sad. As a family, they are trying to “figure out” how to grieve for Daron. Daron’s family lives.

It is now June of 2007, the month Daron would have graduated from high school. Pam has received invitations to several of Daron’s friends’ graduations. She has mixed feelings about attending these events. Daron would have been a graduating senior and with that comes all that has been lost—parties, college anticipation, a graduation trip, a summer job. Pam is grateful to be included, to celebrate the girls who will accomplish these things, yet she finds herself questioning her presence at the parties and graduations. Will seeing her only bring sad feelings that Daron isn’t there? She asks herself, will she be able to “hold up”? She wonders, are they inviting her out of pity or from a place of honor? The grief encompasses, Pam lives.

Pam’s bereavement journey has been challenging: her youngest child has died. The steps Pam took to make an idea—a home funeral—a reality have given her some comfort. Pam returned to work within weeks of Daron’s death. She was welcomed back by coworkers who had walked with her over many months of anticipatory loss. They continue to walk with her. In fact, Pam’s preferred bereavement support has been meeting over coffee in the corporate coffee shop at work with the bereavement counselor. Support groups are not for her. She sometimes emails the hospice team: “They understand what it was like. They were there.” Pam is considering attending the annual National Children’s Memorial Day candle lighting service in December—she was not ready last year. She holds back her tears as much as possible. Pam received a copy of a college application essay written by a close friend of Daron’s. This young woman credits Daron with being a “lifesaver,” providing friendship and support when she was experiencing despair. Pam knows that Daron won’t be forgotten. She knows that she guided her daughter as far as she could go in this life with respect, compassion and love. Daron lives.

The authors thank Daron’s mother, Pam Howley, for permission to share her story—and the two poems by her daughter that appear on page 14.

Jane Fleming has worked as a spiritual care counselor and grief support specialist in hospice for more than 13 years. She coordinates bereavement services for the Stepping Stones Pediatric Program at Providence Hospice of Seattle.

Maureen Horgan has been working with children with life-limiting conditions and their families for over eight years. She is the coordinator for the Stepping Stones Pediatric Hospice Program.

continued on next page
Daron’s Poems

Among Daron’s many interests was writing poetry. While she had written these poems before her diagnosis, her mother, Pam, recalls that she was having some symptoms at the time, and a sense of “knowing” about her future. Pam shared these poems with hospice staff several weeks before her daughter’s death, hoping they would provide depth to Daron’s story.

Sky Blue Tears
A noise sounds silently
As something hits the floor
The cold, hard, ceramic floor
They’re my sky blue tears
Yet they’re crystal clear
Like a broken glass heart
Transparent in the night
Trying to hold on
Trying to fight.

Autumn’s End
The mist sets in the mountains blue
Like anything else that has ever been true
Autumn is nearing its season’s end
While Winter creeps across the land
Snow sets on mountain walls
Frost nips at leaves that fall
Another season’s wonderful sights
As Nature shows beauty and might
A brand new look, a brand new style
While transforming the world in a short, short while.

—Daron Michelle Howley
The comment, at right, from a pediatric palliative care professional illustrates the emotional toil of providing care to children. End-of-life care is intense and emotional, but it is even more so with a pediatric population. How then can hospice and palliative care organizations support staff as they care for children and families coping with life-threatening and terminal illnesses? What mechanisms can providers put in place to ensure that quality staff is able to handle the emotional aspects of the job?

First, we must understand the stress unique to pediatric care professionals. Stress in end-of-life pediatric care is inevitable as caregivers must deal with organizational and team demands, time pressures, ethical dilemmas, and repeated exposure to the tragedy of the death of a child. Barnes published a literature review examining the stress of staff providing children’s hospice care and found that the main causes of stress are conflicts within the staff group, communication problems and role conflict, poor communication with the child’s family, and the inability to relieve distressing symptoms the child may be experiencing.

Organizational Support
Hospice and palliative care programs can acknowledge the difficulty of providing pediatric palliative care by making support available in a variety of ways:

- Encourage/offer opportunities for professional development—this may take the form of sending staff to state and national conferences focused on pediatric palliative care or offering in-services on topics such as symptom management, boundaries, and compassion fatigue;
- Offer staff processing or debriefing sessions after a death;
- Offer staff support or staff bereavement groups;
- Offer staff supervision/consultation on difficult cases;
- Offer staff retreats;
- Make Employee Assistance Programs available to staff and encourage their use;
- Offer memorial services to pediatric staff—a memorial service limited to staff is a very important way to help them acknowledge their grief;

“Some days, I’m so exhausted I feel that when the day is over there will be nothing left of me. But, most days, the rewards I receive are priceless.”

continued on next page
Encourage staff to engage in self-care—especially taking time off to recharge;

Routinely survey staff to assess their satisfaction and needs.

Team Support
Not surprisingly, many team members report that they receive the greatest support from those who are also giving care to dying children and their families. The team of people who care for children and their families is unique in that, as we do our work, many emotional and spiritual chords are touched that affect us and mark us for life. Fears of our children getting sick or being born with a rare genetic disorder are real, and are not easily dismissed as we stare at these situations day in and day out in our work. Our boundaries are blurred by the natural intimacy that forms from the longer length of stay in pediatric patients (due to the resilience and unpredictability of prognosis of this very special population).

It is imperative that we make the time to support one another as we do our all-consuming, rewarding and, at times, exhausting work. Recognizing that we can’t do this alone is the first step. We must lean on one another every step of the way as we assist our patients and families.

Being willing to dance the precarious dance of this work is also helpful. It requires us to be flexible to accommodate team members’ needs regarding schedules, support, etc. while, at the same time, giving ourselves permission to say no when we just need to take a step back because we are feeling overwhelmed or exhausted.

Venting with one another can also achieve closeness and create a deepening bond so we feel comfortable enough to share our positive and/or negative reactions and feelings about the complex situations we are dealing with.

Team members should praise one another when we feel a good job has been done—everybody benefits from sincere recognition of their worth. The intensity, emotional pull, sadness, and closeness inherent in our work asks us to give more of ourselves than other jobs require. Cultivating a sense of camaraderie and humor is helpful because it helps us release tension and feel closer at the same time. And, as one pediatric social worker suggests, “Chocolate also helps!”

Leading by Example
When it comes to establishing boundaries, leading by example is a must. Discussing specific ways to handle common situations that arise with families is important. Such planned discussions help us to anticipate and prepare for difficult and awkward encounters.

Making time to debrief after the death of a pediatric patient is helpful and important as well. Judy Meyer, MSW, shares this practice: “We always attend a pediatric death as a team and make provisions for this if a death occurs during the middle of the night. After the death, the team goes somewhere to debrief—if there’s time—instead of immediately moving on to the next visit.”

Holding periodic team-building sessions is another way to foster healthy and positive interactions between team members. Given the hectic nature of our workday, it can be difficult to make time to get together, but team-building trainings are a good way to keep us on a healthy path and convey new and interesting ways to work cohesively.

Staff support is essential in pediatric hospice and palliative care. Organizations need to recognize that the well-being of the staff is closely linked to the quality of care being given. As individuals, let us encourage one another to give “our all” to patients and families during working hours, but reserve our non-working hours for ourselves and our loved ones.
Living life to the fullest, up to the final moment is what hospice and palliative care are all about.

Palliative care offers comfort and support, while hospice brings you and your family compassionate care when a cure isn’t possible.

Together hospice and palliative care provide solutions beyond traditional medical care.

Hospice/palliative care... It must be love.

Donna Armstrong and Selene Negrette are the pediatric team coordinator and social worker, respectively, for Daniel’s Care, the Pediatric Care Program of Hospice of the Bluegrass in Lexington, Kentucky.

References:
In memory of Gabriel Ricardo Marquez Uppman
May 15, 1997 – November 17, 2000

I pinched the phone between ear and shoulder as the social worker told me what she could do for us. She talked about counseling and finding community resources, both of which I had explored already on my own. “Sorry,” I said, “but I don’t really get the big picture. You just kind of help people?”

“Well, yes,” she acknowledged. “Mine is what you’d call a soft job,”

Soft, I thought.

“How do you know when you’re done?” I asked.

She paused. “Well, that would be when your son, um, dies. I sometimes help families after, you know, the death, but usually my responsibilities end at that point, or we’d try to refer you to bereavement services or something like that.”

I didn’t tell her that’s not what I’d meant. I meant that, at the end of the day, how does she know she’s done her job? How can she tell whether she’s helped someone, or just rounded up a bunch of phone numbers? How can she tell if she’s done any good?

My polite hostility towards our helpers increases daily, and it bothers me. The books say a lot of dying patients and their caregivers become angry with the professionals at one point or another, so this could just be a symptom. But it doesn’t feel like a symptom. What it feels like is—and I know I’m angry, I know I’m not being fair—the people who are paid to participate in this marathon of suffering are the ones with the easy jobs (“soft”), while those of us in the trenches slog it out 24/7 with no benefits and no vacation days. What it feels like is bad, bad luck for us and an office door that shuts at the end of the day for them. It reminds me of American missionaries in the Third World who close their jungle clinic at 5:00 p.m. so the medical staff can take a break. Or the peace corps workers with their care packages of shampoo and treats. What about the starving natives? And how did I become one?

In memory of Gabriel Ricardo Marquez Uppman
May 15, 1997 – November 17, 2000

HOPING THIS COULD BE

Somebody Else’s Life

BY ELIZABETH UPPMAN

Working with families and helping them cope with the impending loss of a child begins by understanding them—their underlying fears, their personal circumstances, their unique needs. For this special issue, we are fortunate that two parents were willing to provide us with their perspective about palliative and hospice care—where it fell short and how it helped.

Elizabeth Uppman, author of this first essay, began receiving services for her 3½-year-old son, Gabriel, during the last months of his life—after more than 20 hospitalizations. “This essay,” Elizabeth told us, “was written a few months after Gabriel’s death. We buried his ashes under a crooked little crabapple tree that blooms gloriously, almost recklessly, in the spring. My daughter Lucia was born a year after her brother died.”

Our thanks to Elizabeth for granting us permission to reprint this essay, which first appeared in Caregiving and Loss: Family Needs, Professional Responses, published by the Hospice Foundation of America in 2003. Our second essay, by Lisa Burman, appears on page 25.
My son Gabriel had the first of many pneumonias at seven months. During that hospitalization he was diagnosed with cerebral palsy, followed later by cortical visual impairment (blindness), reactive airway disease (asthma), and seizure disorder (epilepsy). Now, at three, he has spent more time in hospitals than most people do their entire lives.

It’s the respiratory stuff that brought us to hospice via a gentlemanly senior resident. Funny, I’m not mad at him, though he was the bearer of perhaps the worst news of my life. How kind of him, I thought, how respectful, to take a deep breath and tell us what all the other doctors were thinking: that a toddler with more than 20 hospitalizations for respiratory infections isn’t going to last very long.

When Gabriel first went into hospice, I was simultaneously traumatized and relieved. Just the idea of it seemed so drastic, so hopeless; yet everyone kept telling me how wonderful the people were, how caring and committed. And since we were so used to scrabbling for any little bit of help we could get—allowing the church ladies to bring us dinners, sweet-talking and pleading with and roaring at the HMO—I could half-convince myself that it was just an extension of that, another set of services we could tap.

But it was at the same time an enormous shift and a relinquishing. Finally, I thought, we’re going to be surrounded by people who know what to do and how to help. Finally we won’t have to be the experts anymore. We’ll have someone to share the burden, someone to show us the way. The big step we’d taken of putting ourselves in their hands meant that somebody else could take some big steps now, and big soft wings would enfold us, and we wouldn’t have any more pain.

Turns out the hospice people are just people, not angels. They have opinions, which they tell us, and they fill out forms, which they don’t show us. The nurse comes when we call, listens to Gabriel’s chest, and usually suggests we have some serious discussions about his quality of life. The doctors know Gabriel’s in hospice, but they tell us to take him to the hospital anyway, and the gears grind...
on around him and he is going to die and the gears grind on around him.

Pardon me, but this sucks. And pointing out that lots of dying patients don’t get these services, that you could die in a lot more pain and with a lot less support than Gabriel, does not make me bow my head in appreciation. Gabriel only gets what hospice says he should get. Gabriel gets a nurse’s visit once a week and a lot of people asking how we’re doing and a long, lonesome valley that he has to walk all by himself. No amount of phone numbers from the social worker is going to take that lonesome valley away from him. He’s three years old.

If I were interested in improving this situation, and not just mad about the whole thing, I would offer alternatives. I think a good alternative would be for somebody else’s kid to die. I’d put Gabriel up against any other suffering kid and I have no doubt he’d win the suffering prize. Shouldn’t he get to take his ribbons and trophies and go home? Can’t we all please acknowledge that he’s done his bit and now it’s someone else’s turn?

It would be fun someday to try out the other stages—bargaining, denial—but those just seem like detours. And the thing is, just because I’m angry and anger is a symptom doesn’t mean there’s nothing to be angry about. Let’s quit talking about my feelings, let’s talk about how hospice is failing me. When are they going to start easing the burden? How could they possibly think these few visits, these telephone calls, are sufficient? Who’s with me here? Who’s really with me?

Because it’s not just Gabriel’s turn—it’s my turn, too. I was crushed and overwhelmed when he had to take three different medicines every day. It’s now 10 medicines, and I am still crushed. I was crushed when I had to do his IV infusions (the sterile water, the little alcohol pads). I’m crushed every time I feed him through his feeding tube (the enormous syringe, the sweet, clotted smell). He goes to sleep if you rock him and sing to him, but it’s hard to sing when you are so crushed.

If I am very brave and think very hard about what we’re doing and where we’re going, I realize that I’ve been hoping the nurse and the social worker would take over for me. I’ve been hoping this would start being somebody else’s life. But it’s not somebody else’s, it’s mine: my boy, my pain, and my job, finally, to hold my son’s hand, stroke his hair, and be with him as he dies.

The hospice chaplain wore a shapeless brown dress and told me over French fries that you can have God and you can also have really bad stuff happen to you. Look at the crucifixion, she said. Look how God didn’t jump in and end it. I said, you know, I’m tired of this stuff, miracles for other people, septuplets on magazine covers, and for me a piercing lesson in Christian theology.

At this point, and to her credit, the chaplain didn’t walk through the hospice brochure’s bullet points on “best possible care” and “opportunities for growth.” I should know better than to read the brochures, just as they should know better than to print them. Even though it seems preposterous, you can paint death as a fulfilling spiritual journey—and a mother will believe it, believing anything that promises to take away the pain. Well, I’m here to tell you, this isn’t fulfilling. This is emptying. This is the spinning carnival ride where the floor drops out, you’re splayed against the wall, and you can’t even lift your head to turn away.

I often ask the hospice people if they feel they have a “calling.” It’s the only explanation that makes sense. Me, I wouldn’t be here if I didn’t have to, and it amazes me that someone would choose this. People who take on a hospice career, full of pain, death, and true emergencies (light-years truer than a flat tire or a crashed hard drive)—such people are remarkable. Someday I’ll thank them. But it won’t be any time soon.

These days, the salt of the earth and the milk of human kindness aren’t enough for me. I want a hospice that provides encapsulated lightning bolts for smiting and coupons redeemable for time travel, ubiquity, and omniscience. I don’t think that’s asking for much.

Elizabeth Uppman lives in Overland Park, Kansas with her husband and two daughters. Her essays and poems have appeared in Good Housekeeping, Salon.com, and Brain, Child magazine. Caregiving and Loss: Family Needs, Professional Responses, the anthology in which this essay first appeared, can be purchased online at hospicefoundation.org or nhpco.org/marketplace.
Managing Children’s Pain

By Kaci Osenga, MD

There has been significant progress in the understanding of pediatric pain and symptom management at the end of life. This synopsis serves as a brief overview highlighting important aspects of history and assessment.

In 1993, McLaughlin, et al reported in a study that 99 percent of nurses surveyed believed that newborns experience pain. Unfortunately, only 50 percent of these same nurses felt that analgesia was necessary. Similarly, during the mid 1990s, Tohill and McMorrow found that 70 percent of neonatal intensive care nurses surveyed believed that analgesics were under-prescribed by physicians caring for neonates in their units. In fact, the anatomic pathways and the neurotransmitters that communicate pain are present at a very early stage of development. The pathways and neurotransmitters that ameliorate pain, the endogenous opioids, develop later, however. Thus, for any given painful stimulus, less mature infants are exposed to greater pain signal transmission. In addition, the myth that infants exposed to painful stimuli do not remember the pain is refuted in both the psychology literature and the anatomy/physiology literature.

Children exposed to recurrent painful stimuli as infants develop attachment disorders and are often unable to enjoy physical affection. Toddlers with cancer who survive to become teenagers are able to recall with vivid clarity the pain they endured as a young child. Moreover, there is now striking evidence of permanent changes to the peripheral and central nervous system structures following painful stimuli; these changes are more pronounced the younger the child.

There is a growing body of evidence to suggest that sustained physiologic, anatomic, and behavioral changes can and do result from repetitive and prolonged exposure to noxious stimuli in neonates. Increased sprouting of peripheral nerve endings predisposes infants to more pain when stimulated in these same areas later in life; in addition, changes in the spinal cord (wind-up phenomenon) and in the perceptual cortex predispose to permanent and difficult-to-treat pain syndromes.

Most pain in pediatric diseases comes from invasive diagnostic and therapeutic procedures. This pain is, in large measure, preventable. Alternatively, cancer-associated pain can be a result of the disease. This is common at the time of diagnosis (and commonly abates soon after disease-modifying treatment), relapse, and during end of life. The pain associated with end of life can be severe and rapidly progressive, demanding vigilant monitoring of the child’s condition and a willingness to administer adequate doses of medication to control pain, along with the use of non-pharmacologic techniques aimed at symptom control. 

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management. Wolfe, et al. found that children who died of cancer experienced substantial suffering in the last month of life. In this study, according to parental report, 89 percent of these children experienced substantial suffering from at least one symptom including pain. Unfortunately, fewer than 30 percent of parents reported that the treatment of pain was successful at end of life. Children with end stage HIV (AIDS) also experience disease-associated pain. This pain is usually an associated neuropathy and is commonly difficult to manage. Similarly, patients with end stage HIV (AIDS) may have organomegaly-related pain due to capsular stretching of viscera or infection-related pain, such as headaches due to meningitis, herpes or Candida-related pain.

Similar to adult pain management, it is important to determine the etiology of the child's pain in order to create a treatment plan that is likely to relieve the pain. For example, neuropathic pain, as in end stage HIV (AIDS) and phantom-limb pain, is effectively treated with adjuvant medications in addition to opioids. Pain related to elevated intracranial pressure (e.g., from a brain tumor) could be effectively treated with opioids, steroids, and/or tricyclic antidepressants. Just as for adults, there is no maximum dose of opioid medication for children (WHO Guidelines). One of the most feared side effects of opioids is respiratory depression. Aside from newborns, pediatric patients at highest risk for opioid-induced respiratory depression include those with altered mental status, hemodynamic instability, a history of apnea or underlying dysfunction of ventilatory control, or those with known airway abnormalities.

Because there are many common myths related to pain management in the pediatric population, it is imperative to elicit concerns and fears about the use of pain medications from patients and families. One of the most commonly held beliefs related to aggressive pain management is the fear of addiction. To help debunk this myth, it is important for patients and families to clearly understand the following concepts:

**Dependence:** Also referred to as neuroadaptation, dependence is caused by repeated administration of an opioid that necessitates the continued administration of the drug to prevent the appearance of withdrawal symptoms. This pharmacological/physiological phenomenon is typically seen when opioids are used for more than a few days (usually within 10 days of the initiation of opioid therapy); nevertheless, it does not imply a predisposition to addiction. Evidence of physiologic dependence is the occurrence of withdrawal symptoms upon the abrupt cessation or reversal of opioid analgesics. Withdrawal symptoms typically occur within 24 hours of drug cessation. Dependence occurs with many medications, such as steroids and anticonvulsants, not only opioids; however, when they are indicated, we use these medications and are careful to taper the dose if they are no longer needed. The same should apply to medications that treat pain.

**Addiction:** In contrast to physiologic dependence, addiction is a severe degree of drug abuse and dependence that is an extreme of behavior, in which drug use pervades the total life activity of the user. Patients who are addicted to opioids often spend large amounts of time acquiring or using the drug, abandon social or occupational activities because of drug use, and continue to use the drug despite adverse psychological or physical effects. Anyone who is addicted to an opioid is physically/physiologically dependent; however, not everyone who is physically dependent is addicted. Addiction is a psychological...
phenomenon that is exceedingly uncommon among patients using opioid analgesics to treat pain. It is neither helpful nor accurate to say, “It doesn’t matter if he becomes addicted since he is dying anyway.” Addiction among children is extremely rare.

**Tolerance:** Tolerance is defined as the need for increasing doses of medication to produce the same therapeutic effect over time. This is a physical phenomenon, related to “receptor downregulation.” Tolerance usually develops after 10 to 21 days of morphine administration. It develops to some side effects much more rapidly than to other effects of the same drug. For example, tolerance develops rapidly to the opioid-induced euphoria and respiratory depression, but much more slowly to the gastrointestinal side effects. Many caregivers assume that patients who demand increasing opioid doses are becoming tolerant or addicted. In most cases, patients in pain who demand more drugs usually do so because of their pain. The need for increasing doses of opioids is rarely related to tolerance and is more commonly the result of advancing disease. The development of tolerance to the analgesic effects of opioids in the face of stable disease is minimal and should not be a reason to “save” the opioids until the end. This strategy deprives the child of long-term, appropriate pain control and significantly impairs quality of life. The development of tolerance does not imply a predisposition to the development of addiction.

The literature consistently indicates that the gold standard of pain assessment is self-report. This is difficult, but not impossible, in patients with limited verbal expressiveness, such as infants, patients with severe developmental delay, intubated patients, and toddlers. As Anand and Craig argue, self-reports come in a variety of flavors. As caregivers, we are responsible for understanding the communications of our patients, even if they are not verbal. Changes in behavior such as decreased appetite, increased whininess and clinginess, pained facial expressions, bruxism (grinding of teeth), arching, changes in motor activity or even bowel habits may be a result of pain. While these symptoms are not specific for pain, in the setting where pain is a significantly likely occurrence, a low threshold should be maintained for the administration of pain-relieving medications or procedures. Having a consistent caregiver (often the parent) who knows the patient well is invaluable in assessing pain or discomfort.

**Helpful Hints During Assessment**

**Infants (0-1 year):** After the age of seven months, when stranger anxiety develops, examine the baby in the parent’s lap. Pain-related behaviors may include withdrawal of the affected body part. Avoid abrupt or jerky movements in examining the baby. Usual comfort measures are less effective. Infants do develop anticipatory fear behaviors.

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**Toddlers (1-3 years):** Physical assessment can be assisted by play (e.g., Simon Says, puppets). Minimize initial physical contact. Let the child get used to you and build trust. Praise the child for cooperative behavior. Be sure to use the words familiar to the child in asking questions or giving information. Children often withdraw from social interaction and even play when they are in pain.

**Pre-schoolers (3-6 years):** Children this age like being helpers, having choices, receiving positive reinforcement. They are more independent than toddlers, but like parents close by. They are concerned about having done something to deserve pain and need explicit reassurance that they are not the cause, even if they never indicate they are worried about this.

**School-age children (6-12 years):** These children can understand simple physiology, and cause and effect. They are still concerned about having done something to deserve pain and need explicit reassurance that they are not the cause, even if they never indicate they are worried about this. Children in the older range of this age group are able to use cognitive coping skills.

**Adolescents (12 years and older):** Teenagers need privacy and independence. They are able to use cognitive coping skills. Teens need full explanations, if desired, and input into decisions.

Children often are more willing to discuss hurtful topics (such as being in pain), if non-threatening modes of communication are used, such as play or art. Using the terms they are familiar with and being specific are also helpful techniques. For instance, “How are you doing today?” may result in the answer, “Fine”; whereas “Do you have any bad owies in your leg this morning?” may elicit the opposite answer. Just as for adults, competent management of symptoms demands assessment and reassessment after intervention until the symptom is relieved. An excellent resource for the management of pain and symptoms for pediatric palliative care can be found in the pocket book, *Pediatric Pain and Symptom Management Algorithms for Palliative Care*, by Linda Wrede-Seaman, MD (published in 2005 by Intellicare, Inc.).

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**References:**


In this second essay, parent Lisa Burman reminds us of the immense value that comes from introducing families to palliative care and hospice early in the illness process. Unlike parent Elizabeth Uppman (whose essay appears on page 18), Lisa and her family began receiving services several months before their child was born. “I cannot say enough about how the early connections with palliative care and hospice helped give us confidence in making so many decisions during my pregnancy and during Anna’s little life,” Lisa told us. Our thanks to the Burman family for sharing their experience with us.

Many choose to think of palliative care and hospice to be services for people of all ages who have a life-limiting illness or who are near or at the end of life. Our involvement with both of these services began in the four months before our daughter, Anna, was born. And, to us, both actually meant “life” for fifteen months.

Upon discovery of a serious degree of holoprosencephaly at 20 weeks’ gestation, and the harsh realization that nothing would “fix” Anna’s condition, my husband and I chose to provide comfort care if we were to be fortunate enough to even bring a live baby home. We were opting to do what we believed best for a daughter who would die quite young, and for five other children who would experience a “special” sibling’s life—and death. As parents we had to care for a child with unique needs, maintain a sense of normalcy for Anna’s five older siblings, and do all we could to keep our family intact. Palliative care and hospice made our goal reachable.

We were introduced to palliative care—and the services of the Haslinger Family Pediatric Palliative Care Center at Akron Children’s Hospital—during our second appointment with the case manager at Akron General Hospital. By the time I had my third ultrasound at the nearby Maternal-Fetal Clinic, the nurse from HFPPC, who would later become our connection with the palliative care team, accompanied us to at least three more ultrasound visits before our daughter’s birth. All the while, she and our case manager continued to provide information and answer questions as best they could. Both visited the day after Anna’s birth. The genuine care, concern and compassion which these two showed our family early in the journey helped set the stage for our confidence in caring for Anna at home.

Nearly a month before my due date, I called the local hospice agency and had a follow-up discussion with its grief coordinator, which laid the foundation for our in-home services. I knew about hospice from having worked at a funeral home for a period of time, and became even more familiar with the services during grief groups I led at my church. While I know our case manager would have contacted the hospice for me, I felt the need to do it myself. It was something I wanted to do for my daughter and my family and, I suppose, it provided me with a momentary sense of control.

While making the initial contact with hospice was important to me, so also was the 10 p.m. phone call that we received on July 4—the day we brought Anna home. The on-call hospice nurse introduced herself, saying “Call me if you need anything.” Automatically, a nervous mom was calmed.

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On Tuesday, July 6, we met the hospice primary care nurse, who rather quickly and fondly became known as “Aunt Carol” to our three younger children. Many visits over the next 11 months began by greeting, hugging and holding Anna’s older sisters—then 2 ½- and 4 ½-years-old—before tending to the medical necessities of our little patient. As Anna’s changes were assessed, the hospice nurse or I would have questions for HFPPC’s palliative care team. Those questions would be answered by the same nurse on the HFPPC team. The excellent communication among the three of us gave me and my family the continued confidence we needed to care for our daughter at home.

For my husband, Jeff, hospice’s involvement lifted even more stress from his shoulders. While trying to deal with Anna’s illness and care—and many costly needs—he learned that his last day of employment would be just after Thanksgiving. The hospice social worker said she’d make sure that Anna had formula, diapers, medicines and medical care. And she and “Aunt Carol” also made sure we were always “doing okay.”

My youngest three children also have warm memories of receiving special “gifts” from hospice. On looking back at that time, they have said those gifts made them feel important too. When palliative care staff visited, the older children were addressed first and often asked questions about their sister; they were not left out. The older two boys remember feeling that things would be okay—one said that ‘I seemed to know what I was doing in caring for Anna.’ For Anna’s grandmother, Norma Marko, having help to care for Anna at home was a God-given blessing and privilege. This gave her the chance to develop a relationship with her granddaughter, something that may not have happened if palliative care and hospice had not been our family’s choice.

Trying to select and write about one aspect of having both palliative care and hospice walk the 11-month life journey with us is difficult. Anyone who has had an overall wonderful experience with both of these teams will probably agree. Each occasion of contact was an opportunity for our family to receive genuine concern, compassion, and consistent care. Each was an opportunity for questions to be asked and answered. Each gave us the opportunity to build upon our growing level of confidence. Later contacts, which continued for more than a year after Anna’s passing, were from the chaplains who had been involved, or through hospice mailings. Each and every contact helped build a connection. We felt these teams not only walked alongside us, but had provided the path upon which we walked the journey with our Anna.

Lisa Burman and her family—husband Jeff, mother Norma Marko, and children Andrew, Aaron, Arec, Ava and Audra—live in Minerva, Ohio.
Overcoming the Challenges: An Administrator’s Perspective

By Pam Barrett, ACSW, FACHE

The 2003 Institute of Medicine Report, When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families, won kudos from those seeking to improve care for dying children and their families. Fortunately, the IOM Report continues to spark dialogue and action; it serves as a fundamental resource for those newly considering the addition or expansion of pediatric palliative care services.

However, not all hospices fully embrace the care of children as core to their mission for a variety of stated reasons, such as lack of expertise, lack of human and financial resources, or more pressing priorities. I believe that we must understand and break down the barriers associated with caring for children just as we have for patients with AIDS, end-stage dementia and renal disease.

Perhaps the most significant barriers to accessing pediatric palliative care at the end of life are the issues of prognostication and clarity about treatment goals. Children are most commonly treated aggressively with the hope of extending survival, even in the face of a serious illness or life-threatening condition. Thus, traditional hospice care—with its requirement for a six-month-or-less prognosis and expectation to forego curative treatment—is not easily embraced by parents or the medical community. We must understand this reality and meet patients and families where they are; knowing that children and their families suffer physically, emotionally and spiritually and that we have the expertise to extend support, it is our ethical responsibility to do so.

Organizations Stepping Up to Meet the Need

Many long-established hospices in this country have been quietly serving children and families, but in relatively small numbers, with limited resources and without fanfare. Thus, the constituency group can easily be overlooked. There is little research regarding the needs of dying children. Louder voices for the expenditure of limited healthcare dollars are heard over those of advocates for palliative care for children.

The pediatric program in Buffalo dates back to 1988, when services were first offered as part of the Children’s Hospital of Buffalo and operated through a home health program. The program transferred to The Center for Hospice and Palliative Care in 1998, allowing the program continued on next page
to expand services and provide greater access to children and families by offering services via home health and hospice benefits. Appropriately, the program is now known as *Essential Care for Children*. The dually licensed hospice/home health programs, which also utilize community donations to support their pediatric programs, are most typically leading the way in serving medically fragile children.

*The Hospice of the Florida Suncoast* is another program that has been able to serve pediatric patients in a flexible manner. Initially offering nonmedical services, dating back to the early 1980s, the program has evolved to provide comprehensive hospice and palliative care services. Stacy Orloff, director of the program’s Palliative Care and Children’s Services, says that while “it may be hard to predict how and when a child dies, children can benefit from the same holistic and interdisciplinary care that adults receive.” Like other pediatric-friendly hospices, this program must rely heavily on the generosity of donors to subsidize care for children and families. Fortunately, changes in Medicaid funding in Florida should help increase children’s services.

In 2000, a grant was obtained by Children’s Hospice International to help develop Medicaid waiver programs in Colorado, Florida, Kentucky, New York, Utah and Virginia but, thus far, only Florida has an operational program while one other state has passed waiver legislation. These initiatives are referred to by Children’s Hospice International as CHI PACC® (Children’s Hospice International Program for All-Inclusive Care for Children and their Families®) and the concept behind them is sound: to develop demonstration sites which provide a continuum of care for children and their families from time of diagnosis (with hope for a cure) through bereavement (if a cure is not obtained). Yet, these efforts have been slow to become funded and operational.

I am particularly intrigued by the efforts (outside the CHI PACC® states) which are finding success and extending comprehensive, high-quality palliative, hospice and bereavement services to children and families. These programs have developed despite limited or nonexistent resources from bureaucracies slow to understand or embrace the unique needs of dying children. These programs may be in states not likely to achieve a Medicaid waiver program, yet they have persisted despite the odds. In fact, some of these programs have made greater strides than in the identified CHI PACC® states where advocates labor tirelessly for an operational Medicaid waiver program.

*Kids Path®* is one such program. Founded by Hospice and Palliative Care in Greensboro, North Carolina, Kids Path® is a specialized consortium of 10 community-based providers—with seven located in North Carolina, two in South Carolina and one in West Virginia.

Members of this consortium provide care for a significant concentration of children with progressive and life-threatening conditions, with over 200 pediatric patients being served last year. Common admission criteria are used, offering more flexibility than traditional hospice care. This consortium also provides significant networking opportunities for its members, enhancing and energizing the work of the individual programs. Marion Taylor, the Kids Path® director and a pediatric nurse practitioner with over 20 years of hospice experience, delights in sharing stories—from symptom management success to filling the wish for a dying child to meet Spider-Man; it is all about enhancing quality of life.

*The Children’s Hospice and Palliative Care Coalition* of California, initiated by Lori Butterworth and Deavon Dabbs, is having legislative success with Tender Mercies, a new Medi-Cal Benefit to support children with life-threatening conditions. In addition, advocacy extends to developing model site locations for palliative care offerings and a support network for parents. As with all successes, it is clear that champions are needed—and often from collaborative sources outside the provider community. (For more about this coalition’s network for parents, see page 45.)

State hospice associations can be integral to advancing education about and funding for pediatric palliative care. Last year, the Hospice and Palliative Care Federation of Massachusetts was successful in getting legislation passed to fund a unique pediatric palliative care program in which 10 hospice programs are contracted to provide services.
Pam Barrett is executive vice president for organizational excellence for Hospice & Palliative Care Charlotte Region, based in Charlotte, North Carolina. Before relocating last spring, Pam served for 22 years as the CEO for Hospice and Palliative Care of Greensboro, where the Kids Path® program was founded. A frequent speaker for NHPCO, Pam has also served on the NHPCO and National Hospice Foundation boards of directors.

Having a champion in the legislature was a key factor in the organization’s success, according to Rigney Cunningham, director of the Federation. Kathy McMahon, president of the Hospice and Palliative Care Association of New York State, agrees. “You can’t give up,” she says, “You must develop champions within state legislatures and Medicaid offices.” Recently, New York State finally passed a $700,000 bill authorizing additional pilot sites for the NY PACC program after many years of effort.

There is a significant and well-documented upward trend in hospital-based palliative care services for adults, but pediatric services are also being developed. An example I am most familiar with is The Neonatal and Pediatric Program of Levine Children’s Hospital at Carolinas Medical Center in North Carolina, established in late 2005 in collaboration with Hospice & Palliative Care Charlotte Region, to address the needs of children and families who face life-threatening diagnoses. In addition to the RN coordinator who was selected in part because of her extensive critical care background (the ICU setting is where approximately 85 percent of childhood deaths have traditionally occurred), a social worker and hospice pediatrician are part of the pediatric palliative care team. Together, they will serve a minimum of 60 children this year. Close collaboration with the local Kids Path® program enables an increasing number of children to be cared for—and to die—at home.

In fact, the place of death for children with complex conditions is shifting, according to a recent JAMA article (Shifting Place of Death Among Children with Complex Chronic Conditions in the United States, 1989-2003; June 27, 2007-Vol 297 No.24). The authors conclude their findings by stating that “the capability of home-based hospice and home nursing agencies to provide care to meet the needs of (these) pediatric patients for palliative care, needs to be assessed and expanded.”

Yes, indeed. Champions for children and visionary leaders are making it happen. Perhaps those who are reading this issue are those who will break down the barriers and ensure access to state-of-the-art care at the end of life. We must do this for the little people.
As we look closer at what open access means to each hospice organization, we need to make certain that we do not forget the pediatric population. As hospice professionals, we know that the sooner the hospice referral occurs, the more time we have to work with the patient as well as their family, including offering support to siblings. It also allows us more time to assist in meeting the needs of friends and the school support system.

Do you participate in providing end of life or palliative care for the pediatric population? If so, does the criteria for admission and care look different from that of an adult? It should. As difficult as it is to predict prognosis in an adult, the pediatric population is even more challenging. Whether the life-threatening condition is due to congenital defects, accident, or illness, this is a population that not only deserves to receive hospice and palliative care, but can also benefit from the support services and expertise we offer.

There are clearly benefits and barriers in providing care to pediatric patients. One of the greatest barriers is that we do not expect children to die. Knowing this, we need staff who are trained and supported in the delivery of this type of care. Unlike providing hospice care to an adult, staff providing care to a child needs to be comfortable with uncertain survival time and what may be complex medical treatment plans. Local pediatricians can be helpful in addressing these challenges.

Among the benefits is our expertise—as hospice professionals, we can offer a great deal to children who are living with and dying from a terminal illness. We can help prevent unnecessary symptoms, assist with effective communication and support, and can help the child and family identify and achieve their goals while preparing for the eventual death.

As we make an intentional commitment to open access, we need to recognize that this includes pediatric palliative care. Children deserve to have this expertise just as the adult population does. Families, friends and schools also need access to this expertise while they are caring for a terminally ill child.

Teresa McCready has worked for Hospice of Lancaster County in Lancaster, Pennsylvania for the past 22 years, and is currently the program’s access services manager. Teresa is also a member of NCHPP’s Nurse Steering Committee.
The volunteers of BJC HealthCare’s pediatric hospice, Wings, come in a variety of ages, with unique talents and skills that make a difference for our families. Wings is the only pediatric hospice and supportive care facility in the St. Louis, Missouri area and serves about 100 patients per year.

One of the youngest volunteers, 12-year-old Samantha Shanker, started volunteering by baking cookies for Wings’ families. She and her aunt baked 50-100 cookies per family and delivered them personally in pretty, packaged baskets. Shanker has expanded her volunteer project by making comfort bags for patients and their families that contain such donated items as lotion, lip gloss, hairbrushes, small toys, and books. She is also in charge of writing letters to companies for donations and has made fliers to pass out to friends and neighbors. “The bags let the families know that someone is thinking of them” she says.

Two volunteers even younger than Shanker are the Dalmatians, Nel and Ami, owned by volunteer June Brennan-Mueller. Dressed in costumes, usually including a hat, the dogs visit children receiving services in the hospital or at home. Children who have been unresponsive to staff are sometimes freed from fear and talk openly to Nel and Ami. The dogs can be a helpful bridge in connecting with a patient’s siblings too. “Sometimes siblings get lost in the shuffle,” Mueller says. “Siblings remember the dogs from home visits and then see them at our grief camp, Stepping Stones, or during group grief sessions.”
At Stepping Stones, approximately 150 volunteers contribute time to help siblings of the deceased child work through the grief process. The camp offers bereavement and remembrance activities that are carefully balanced with light-hearted activities too. For example, volunteer Marky-Mark, the clown, has entertained for years during the camp carnival while volunteer, Duct Tape Man, has performed laughter-rousing skits. Nel and Ami also make their appearance.

Students from the local Kirkwood and MICDS high schools also spend time with the pediatric patients and families—especially siblings—as part of their school’s community service requirement. The students may go on outings with the families or visit their homes, where they play games or chat with a patient’s siblings.

Another of the program’s volunteer services is named after a former Wings patient. Through “Mackenzie’s Gift,” parents receive a free massage as stress relief or, if they prefer, a gift card to a restaurant or movie.

Several volunteers also use their special talents to comfort the families of children. Carol Burns sews pillows in honor and memory of the patient. First, squares of material are selected to make the patchwork top and are then sent to the child’s school where classmates will draw or write notes on them about their friend. Burns then quits the squares together, and assembles the pillow, and staff bring it to the family as a keepsake. Other volunteers create teddy bears, made from an item of clothing belonging to the patient and chosen by the parent.

Another talented volunteer creates keepsakes, using her photography skills. Her black and white photographs may be of a child who is receiving supportive or hospice care, or of a baby that is stillborn or born with little chance to live. She does touch-up work to remove bruises, skin discoloration or tubes. Since many parents are unable to take the child to a photo studio, these may be the only professional photographs a parent will have of his or her child. The cost for the photography is paid for through donations to the Wings program.

Businesses also donate their time and funds to Wings. Tech Electronics, Inc., for example, makes sure that Wings patients have wonderful birthdays. The patient’s social worker will ask what gift the child may like for his or her birthday and how many children would attend if there was a party. That information is given to the staff at Tech Electronics who prepare and/or purchase all the makings for the party. On the party day, the social worker receives the wrapped gift, a decorated cake, party food, decorations and balloons.

Another fundraising group is the Friends of Wings. This group was started in 2002 by St. Louisan Asha Zimmerman, who was touched by a newspaper article about a young boy who was able to spend his final days at home with help from Wings. Since the group’s inception, members have planned and hosted numerous fundraising events. The donations they raise benefit families whose care is not covered by insurance and help fund the purchase of holiday gifts for family members.

“BJC Hospice’s Wings volunteers are highly valued by our staff,” says Eileen Spinner, the program’s volunteer coordinator. “Without their compassion and incredible ability to reach out to the patient and the family, we would not be able to provide the care and comfort we do. They are truly an integral part of the Wings team.”

Margie Schaffer is a communications and marketing specialist for BJC HealthCare in St. Louis, Missouri, where she has worked for 11 years.
As the alarm is going off, I’m still a little groggy from my ER shift of the night before. A call from Sara, one of our two pediatric nurses at The Hospice of the Florida Suncoast, confirms that we have at least one home visit after the Tuesday morning IDT meeting. The temperature outside is 79 degrees and it’s only 8 a.m. I’m wishing I could go to work in shorts and a T-shirt!

After my customary two pieces of peanut butter toast and black coffee, I’m off to fight the traffic in the most densely populated county in Florida. I feel fortunate that the main office recently moved and is actually closer to my home by almost 10 minutes. Despite the sunny weather, the drivers on the Bayside Bridge are quite crabby today.

The IDT meeting takes about two hours and we start by discussing the patients who are stable, at least for the moment. We have a darling 3-year-old with a diffuse pontine glioma who is a little more unsteady; a very bright teenager with Ewing’s sarcoma of his right femur with multiple metastases to lung and liver who is scheduled for ablation of five pulmonary tumors later today; and a 4-year-old with a rare mitochondrial disorder. In addition, we have an adorable 6-month-old with inoperable congenital heart disease who is just starting to show some early signs of congestive heart failure, so we decide to start Lasix and gauge his response. Then there are the myriad of children with neurological disorders—brain tumors with diabetes insipidus, near drownings (all too common in Florida), hydrocephalus with Dandy-Walker malformation, and several kids with Otahara syndrome. And these are the relatively stable patients. Unfortunately, we also have two children who are not doing well—which I’ll tell you about later.

Today at IDT, we have a first-year pediatric resident with us as part of her community outreach education. After the IDT is over we discuss the “medical” aspects of hospice care—pain and symptom management.
She has only a brief time with us, but we believe the residency program will be increasing the exposure to end-of-life care in the future.

Sara and I grab a quick lunch at the Blue Heron (sounds fancy but is definitely not), and head for our first home visit.

The home is in a beautiful residential neighborhood. This brave little 12-year-old girl has been ravaged by Langerhans Cell Histiocytosis with multi-system involvement and many painful bony lesions, including numerous skull lesions. She has been struggling with this disease for years. The entire team has been at this home numerous times and they seem like family. The parents are exhausted. Her oral pain meds are no longer working, she cannot eat, and her weight is down to 80 pounds. We call the family’s social worker, Amanda, to alert her to the patient’s change. Amanda tells us that she’ll stop by later and to make sure the family knows to page her if they need her sooner.

At this point our patient is literally skin and bones. We decide to put her on SQ Dilaudid to control her pain, knowing that the end is near and her struggle will soon be over. I will never forget the desperation in her parents’ eyes. We linger as long as possible, knowing that no words can take away the family’s pain. They have all fought so hard for so long. Eventually, her pain seems to improve and we know we have to visit another child.

Our next visit is in south St. Petersburg, which is roughly a 40-minute drive on Interstate 275. Now, I’m out with Jann, our other pediatric nurse. We take her car to avoid having to park two cars in a limited space. The patient is an 8-year-old girl who is dying of leukemia. She and her mom live in a tiny upstairs apartment, accessible only by a rickety flight of stairs. I am seriously concerned that it will not support the two of us.

The mom recently signed a Do Not Attempt Resuscitation order when there were no further treatment options. The family lacks adequate financial resources and our social workers have spent hours making sure her electricity is not cut off. Our patient is dependent on her oxygen concentrator and needs electricity to run it! Despite the electricity being on, the apartment is sweltering and the poor little girl is lying on an old sofa, drenched in sweat. What a contrast from our last visit in a beautiful, fully air conditioned house! But despite the stark contrasts, the look in her mother’s eyes is no different. What is it about the eyes? The fear, exhaustion, desperation, helplessness, and uncertainty all blend into that “one look” that is like no other.

We adjust our patient’s oxygen and pain meds and vow to help with the electric company and other bills as best we can. In fact, as we’re chatting, another social worker on our team comes for her weekly visit—it’s good to have most of the team gathered together at the patient’s home. The mom wants to know how long her daughter will live and we say days, not weeks. I am continually amazed at our psychosocial staff and the job that they do helping families. They have infinite patience which I cannot say is one of my strengths.

The drive home in late afternoon is somber. The two children we just visited will die long before their time. We get back to the main service center just before rush hour and head for home. My wife greets me at the door and gives me a big hug—she knows better than anyone about the emotional drain associated with my job.

Tomorrow is a planning meeting for an inpatient palliative care program at All Children’s Hospital. I review a couple of articles, watch the tube for a while, and then head to bed. But I find myself laying awake and still seeing those eyes.
Training Providers and Bringing Services Together

By Stacy Remke, MSW, LICSW, and Joan Ramer Chrastek, MSN, CHPN

Until recently, most hospice and palliative care initiatives have been focused on adults. In 2003, Children’s Hospitals and Clinics of Minnesota developed the Children’s Institute for Palliative Care (CIPC) pilot project to improve training in pediatric palliative care as well as access to services in the five-state upper Midwest region. Here we describe the project’s goals, planning, implementation, and results as well as the lessons learned.

The Project’s Goals
CIPC’s goals were established based upon recommendations from the Institute of Medicine* and a Minnesota Commission on End of Life Care Report. They were to: (1) provide training and support to increase access to pediatric palliative care in the region; (2) develop and maintain a central resource for pediatric palliative care; and (3) develop and support a network of providers.

A professional advisory group comprised of international leaders in the field (see sidebar on page 39) provided guidance and direction as the training program developed. Leadership included practitioners with expertise in pediatrics, pediatric palliative care, and hospice care. The program coordinator, an MSW experienced in pediatric palliative care, worked closely with an interdisciplinary team of health professionals to ensure that educational and resource objectives were tailored to the needs of diverse practitioners in the field. The project’s components were focused in four areas:

1. Education, including seminars and practicum for healthcare professionals;
2. Professional consultation, including a 24/7 on-call service;
3. Outreach, including technical assistance and consultation for programs to develop pediatric palliative care services;
4. Resources, including a lending library of materials for professionals, families and children.

CIPC’s Building Block: Ahlaya Seminars
Ahlaya is an ancient Sanskrit word which means “shelter,” and was chosen as the name of the pediatric palliative care seminars because shelter from disease is what palliative care seeks to provide. These
seminars became the central building block of the training program. They offered comprehensive and state-of-the-art training in pediatric palliative care. A series of three two-day seminars were designed to teach practitioners from pediatric hospital and adult hospice programs—in both urban and rural settings. The multidisciplinary group of participants included hospital and community-based practitioners.

Objectives and specific resources for content were adapted from the Children’s Project on Palliative/Hospice Services’ (ChiPPS) Education and Training Curriculum for Pediatric Palliative Care (see References on page 39). Objectives for the first seminar included:

- Understanding and becoming acquainted with the history and principles of the hospice and palliative care movement;
- Identifying basic principles of pediatric palliative care and differentiating them from adult hospice care;
- Describing the main life-threatening conditions of childhood and adolescence; and
- Understanding family systems and the changes they encounter when a child or adolescent has a life-threatening condition or is facing impending death.

CIPC’s advisory group participated in planning the sessions, suggesting speakers, and defining strategies for interdisciplinary learning.

One of the challenges in designing the seminars was the complexity of the materials to be covered. Another was the unknown knowledge base and diversity of the attendees. Some had extensive pediatric experience but no hospice experience, while others had adult hospice expertise but no experience with children. Very few participants had experience in both areas. It was important to address the needs of all participants. This was accomplished by deliberately planning a flexible curriculum that could adjust to the attendees’ educational needs. Specific conference staff members were identified as contacts to whom feedback could be directed. As issues were identified during the course of the workshop, these staff then offered informal small-group sessions around various topics tailored to address the needs.

The educational process emphasized palliative care philosophy and clinical skill development. The content was organized around what experienced clinicians felt practitioners in the field would need to know in order to provide effective pediatric palliative care. The faculty members recruited were experienced practitioners and leaders in the field who were able to share concepts and stories that illustrated their practical application. Attendees especially appreciated anecdotes that modeled interactions with children and families.

For example, one common question was, “What do you do if the parents ask you not to tell the child that he/she is dying?” The presenters gave examples of how staff could approach parents on this issue: “I really appreciate your concern for your child and your deep love for them. You know often we have found that children really do know what is going on and don’t say anything because they are trying to protect their parents. Your child is very sensitive and is able to pick up on many things. It may be that he/she already knows. I promise I won’t bring up the subject to him/her—but if he/she asks I cannot lie. If he/she does ask, how would you like me to respond?”

It was personal stories like this—applicable to everyday occurrences—that really hit home. According to feedback from participants, the stories from experienced clinicians were identified as a highlight of the training.

Because of the unknown learning needs, the faculty built flexibility into the seminars. The planning group anticipated that close monitoring of the group’s needs and feedback could be incorporated into the training as the sessions progressed. Experienced faculty, who were experts in their field, made this possible. At times, the planned agenda was discarded in the interest of meeting the immediate needs of the group. For example, a physician presenter adapted her presentation on the spot (after consulting with organizers) to address the needs of attendees who wanted to learn more about the emotional aspects of care.

Hands-on learning was an important part of the seminars. Attendees were given a sample toy kit to help orient them to strategies for engaging children. These were small, colorful cloth bags...
with bubbles, Slinky® toys, smooth stones and art supplies. These were designed to illustrate that “kid friendly” strategies can be inexpensive and easy to replicate. An integrative therapy “fair”—consisting of experiential booths featuring modalities such as aromatherapy, massage, energy work and acupuncture—was also offered. With this knowledge, attendees could provide better informed recommendations for adjunctive therapies to patients and families.

In all, over 75 people attended the seminars from five states in the region. About 50 percent were nurses, 25 percent were social workers, and 25 percent represented other disciplines, including child life specialists, chaplains and physicians. The presenters were given objectives from the ChiPPS manual, and were asked to tailor their content around those. This allowed faculty discretion on how best to teach their topics. As a result, attendees were exposed to a range of teaching styles.

**Outcomes and Results**
Learning in the Ahlaya seminars was assessed through pre- and post-surveys. The results indicated a marked improvement in knowledge in each objective area, with one notable exception: Participants reported knowing less after the seminar regarding cultural competency. As one participant said, “I didn't know what I didn't know!” Other participants repeated this sentiment, saying they too would have rated their knowledge lower at the beginning had they realized how much there was to learn.

Because of the Ahlaya seminars, a regional network of trained providers now exists. Providers have access to information about state-of-the-art pediatric palliative care as well as 24/7 interdisciplinary, pediatric-specific consultations. Because many of the members of the CIPC Consult team were also faculty at the training seminars, participants using the phone consultation program have the benefit of already knowing and trusting the experts with whom they are speaking.

**Lessons Learned**

**Recruitment for Seminars Must Be Personal**
Marketing and recruitment for the seminars proved to be a challenge. The carefully developed mailing lists did not reach their target. Many people were unfamiliar with the aims and goals of this new field and needed to learn more about the rationale for education in this area before making a commitment to attend. Shortly before the first conference, registration was low. To boost registration, CIPC staff members called known contacts and identified programs—and that personal contact made a difference. As word spread, requests for additional seminars and education increased.

**Engaging Physicians Requires Extra Effort**
Physicians did attend the seminars, but not in large numbers. In part, this may reflect the newness of this specialty field as well as
general competition for busy physicians’ time and attention. Planners subsequently heard that groups in other areas of the country had run into similar barriers in efforts to engage physicians. One issue of significance to physician participation was the denial of continuing medical education (CME) credits. The denial was based on the interdisciplinary nature of the seminars and the fact they did not focus enough on the specific training needs of physicians. In spite of this setback, several physicians attended all six training days and have since emerged as regional leaders in this specialty area. Learning from this initial failure, CIPC has since gained CME approval for other training events.

**Participants Want Real Examples**
The attendees were clear they wanted practical education. They wanted to know how to respond and care for families. Attendees repeatedly requested not only theory, but also stories of how experienced clinicians intervened. Organizers quickly received feedback that stories and case discussions with clinicians were preferred to small-group discussions with others new to the field. Modeling effective intervention strategies turned out to be an important and effective learning tool.

**Practicum Must Be Flexible**
While many participants expressed interest in practicum learning opportunities, they found it difficult to carve out the necessary time from their already busy schedules. To accommodate participants, practicum experiences have been offered as a component of training at no cost, with participants paying only for their travel expenses. Placements have ranged from one day...to a few days...to several weeks. CIPC staff members work with applicants to design a schedule of activities that match their individualized learning needs and interests. Practicum participants have been able to attend staff meetings and patient rounds, meet with authorization and billing specialists, and accompany clinical staff from various disciplines on home and hospital visits. They have been part of new intakes, have met with the resident ethicist at our program, and observed the workings of the integrative medicine clinic.

**Institutional Support is Essential**
We could not have accomplished this project without significant institutional support. As this field grows, a certain amount of support and funding is necessary to allow providers to gain skills, develop linkages, and network to provide effective care. Children’s Hospitals and Clinics of Minnesota provided support in many ways—through communications and marketing as well as with assistance in obtaining continuing education credits for seminars. Collaboration within the hospital as well as with home-care communities was strongly supported by CIPC and was instrumental in ensuring success.

**Next Steps**
Planning for additional trainings has been started. Plans include revising the Ahlaya seminars to reflect lessons learned, and to encompass other curricula that have recently emerged in this field (e.g., IPPC, ELNEC-Peds). Based on participant feedback, the program will emphasize developmental issues, pain and symptom management strategies, and regional network and resource building.

In order to meet the expressed needs of participants from rural areas, CIPC will also offer several core content trainings in areas outside of the Twin Cities metropolitan area, and throughout the region. The program was able to secure private philanthropic funding for this initiative based upon the success of other CIPC projects. As local expertise expands, it is anticipated that future trainings can be conducted with local faculty, using “train the trainer” models, which will help reduce training costs over time.

Efforts to publicize the resources and activities of CIPC are ongoing since we recognize that they are only useful if practitioners and families are aware of and have access to them. We are also continually developing web-based information to enable practitioners, and families in particular, to have easy access to the information and services.

It will be important to embed these successful strategies into existing programs and services within the organization and the community in order to ensure that they remain available even as allocated federal funding runs out. To that end, staff are working closely with educational institutions, professional bodies and the community to develop linkages and commitments.
to include pediatric palliative care in all aspects of care for children with life-threatening conditions and their families.

**In Conclusion**
We have found the combination of academic and practical education to be successful in promoting pediatric palliative care in the upper Midwest region. This is evident from participants’ feedback, increased access to services by children, and growth in the regional provider network. Together, seminar-style training, the development of a central resource, access to 24/7 consultation, and technical assistance have proven to be essential components of this successful model—along with a good sense of humor and grace!

Stacy S. Remke is the coordinator and co-founder of the CIPC program, and a clinical social worker with the homecare, pain and palliative care programs at Children’s Hospitals and Clinics of MN. She has 20 years of experience in pediatric care.

Joan Ramer Chrastek is the coordinator for Pain and Palliative Care for Children’s Hospitals and Clinics of MN and co-founder of CIPC. She has worked in hospice and palliative care for over 20 years, and has published and presented nationally and internationally on issues of pediatric palliative care.

**References:**


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In 1999, filmmaker Mark Meyers and his wife, Tenya, learned that their newborn son, Kaymen, had severe cerebral palsy—leaving him with no ability to hear, to see or to suck/swallow; only his brain stem was functioning. At the time, the Meyers were not at all familiar with hospice care, but today they count themselves among the field’s strongest advocates. Here Mark talks about the experience as well as the public service announcement he is creating to raise awareness and contribute to a cause he now believes in.

How did you finally learn about palliative and hospice care for your son?
We learned about it through the West Side Regional Center in Los Angeles and our pediatrician, Dr. Richard Levy.

What was your initial reaction to hearing the “H” word?
Nervous and scared, but at the same time we found comfort in knowing that someone was going to help us through this situation.

What did you and your wife find most helpful about the services you received?
The love hospice brought into our house. I will never forget when the hospice nurse, Kelly Klem, entered our home for the very first time. She stopped, looked around, took a deep breath, smiled and said, “I can’t believe it! This house is filled with so much love and positive energy. I can feel it flowing through the air. This is good. You guys are going to be just fine. Kaymen is going to be just fine.” She walked over and gave us both a huge hug and kiss, and told us that Kaymen was very lucky to have us as his parents.

After days upon days of seeing our son in this condition and still alive, we became frustrated about when he was going to die. Kelly taught us that this was Kaymen’s time and he was going to decide when he was going to die. Kelly explained that this is the first time Kaymen is going to get to make a decision. When he dies will be up to him. Let him have his turn. Let him decide. Kelly taught us to surrender. This saved us.

What motivated you to produce this PSA about hospice care?
To change the world’s first impression of hospice. If people have more of an understanding that hospice is about living, they will be more open to it. They will be able to help themselves or someone they know who is struggling with end-of-life decisions—not only for the person who is dying, but also for the people who survive that person. If we can bring more awareness to people, we can help people and we can save people.

How is this PSA different from others that have been created for hospice in the past?
I went to hospice a year ago with a crazy idea—let’s do something that people are not expecting from hospice. Let’s catch them off guard, get their attention, and send as much love their way as possible. Let’s make it a more abstract message filled with animation and a world we have not seen before. Let’s make it ‘its very own fairy tale.’ Then I heard the song, “It Must Be Love,” by the
Mark at work on the Hospice PSA, “It Must Be Love.”

band Madness and had to have it. I showed the band and the record label company the concept and they granted us the rights to the song for this purpose. And now here we are. I hope everybody enjoys it.

Did the process of creating the PSA help you at a personal level?
Absolutely. Creating this PSA was something I felt I needed to do for a long time. It was something I needed to express on behalf of my son and the experience he gave me.

Even though my son is not physically with me, his energy and love is abundant in this message. It feels good to do something that will help people.

How are you and your wife doing now?
Tenya and I have three other children and a fourth on the way. Julian is 7, Bella is 5, and Lotus is almost 2. We adopted Lotus from Vietnam when she was 5-months old. I think our lives are very good and well rounded. We have our good days and bad days. And all you can do is take it day by day, and do the best to make the most of the moment.

NHPCO extends special thanks to the Meyers for their time, talent, and financial commitment to this valuable project. The PSA points to itmustbelove.org where visitors will find information on hospice provided by Caring Connections. We are proud to support their creative efforts.

Creating this PSA was something I felt I needed to do.... Even though my son is not physically with me, his energy and love is abundant in this message.
A Call for Change

The Children's Project on Palliative/Hospice Services (ChiPPS) is a group of professionals who are working together to enhance the science, practice, and availability of pediatric palliative and hospice care. Since its inception in 1998, ChiPPS has made valuable contributions to the field, including the development of educational materials that can help organizations serve the needs of children more effectively.

Among these materials is “A Call for Change: Key Recommendations,” which we are pleased to reprint below. NHPCO members can also access this document—and other helpful information—from the ChiPPS section of NHPCO’s Web site: nhpco.org/pediatrics.

Clinical Care Recommendations:

- The sole admission criterion for pediatric palliative care services must be that the child is not predicted to survive to become an adult. Prognosis for short-term survival should not be required, as it is very difficult to predict, interfering with access to palliative care needed to provide appropriate family-centered support from the time of diagnosis of a potentially life-threatening condition.
- Reimbursement patterns must be changed to place value on comprehensive care for children living with life-threatening conditions, including excellent communication and counseling; aggressive pain and symptom management; coordinated, seamless care between settings and healthcare episodes; and grief and bereavement support for the child and family.
- Interdisciplinary care team meetings are critically important to proper management of the illness, associated physical symptoms, psychosocial and spiritual issues.
- Families should have unlimited access to their children, regardless of the care setting.
- Providers who care for children living with and dying from life-threatening conditions encounter losses and may experience stress; provision of support for staff should be a mandatory component of pediatric palliative care services. Reimbursement for services should factor in an allowance for this.
- Hospice or independent grief counselors should be available to consult with or be employed by hospitals. Post-death care for families and medical care providers should be included in programmatic healthcare design and funding.
- Provision of support services to the affected child's teacher, classmates, and schoolmates and members of community organizations who care about the child is a compassionate, reasoned, and cost-efficient response to the critical illness and death of a child.

Education Recommendations:

- There are currently very few providers of any discipline that are familiar with pediatric palliative care. The need for education is urgent. Thus, financial incentives for training in pediatric palliative care must be made available. Tuition sponsorship and discounted liability coverage or bonuses are options to consider. Institutions that make palliative care a priority should receive tangible assistance.
- Sufficient resources must be allocated for the development and implementation of innovative training programs in palliative care in schools of medicine, nursing, and social work. Minimal standards for program content and competency-based testing must be developed.
- Residency and fellowship programs in pediatrics must incorporate pediatric-specific palliative care information. Continuing education programs and certification will rapidly make urgently needed pediatric palliative care more available and accessible.
- Appropriate faculty expertise, time and resources must be mandated to address pediatric palliative care issues. Health professions schools must commit to the availability of qualified faculty experienced in palliative care and supportive services.
- Training in pediatric palliative care for home care and hospice workers, nonprofessional
caregivers, parent aides, and volunteers must be provided to enable competent care for children living with life-threatening conditions, particularly in the terminal phase.

- Counselors, psychologists, schoolteachers and officials need training to effectively accommodate the needs of terminally ill children as well as their classmates.

**Legal and Ethical Recommendations:**

- Good Samaritan legislation must be enacted to enable parent-to-parent respite cooperatives and referral.

- The concept of pediatric assent should be actively taught and embraced in policy and law. Extending the mature minor doctrine to children with capacity for medical decision-making regardless of age should be supported in state, institutional and reimbursement policies. Tools to assess minors’ capacity to participate in decision-making are desperately needed.

- The use of the school as an expensive and inefficient *de facto* respite provider should be revisited.

- Orders to forgo resuscitative efforts (“DNR”) outside of hospitals must be honored in school and other public and non-hospital settings by the emergency medical system.

**Research Recommendations:**

- Adequate funding for research in pediatric palliative care must be allocated. Only then will children and families be assured that the child is receiving proven therapies. Outcome measures relevant to the child and family must be developed. Continued extrapolations from adult data is unethical; over and over it has been shown that children are not small adults, physically, psychologically, emotionally or otherwise. Research to be applied to children must be derived from children and their families. Research should build on evidence that already exists, be innovative, and fill existing gaps in service.

  - Specific and urgent research issues include the utility of care coordinators to orchestrate the care of the child, the effectiveness of parent education tools to ensure informed consent, the effectiveness of sibling interventions to improve bereavement outcomes, and the safety and effectiveness of treatment and prevention of pain and other symptoms.

  - Tools to assess the quality of and satisfaction with pediatric palliative care must be adapted and tested.

  - The associated costs of palliative care interventions should also be tracked.

- Standards for the provision and reimbursement of pediatric palliative care services need further development and need to be integrated into the larger healthcare system.
Yes,
you can maintain relationships with your community pharmacy!

Hospice Pharmacia utilizes a pharmacy network of more than 60,000 pharmacies nationwide for medication access. So, YES, you can partner with HP for comprehensive medication management services and still maintain relationships with your preferred community pharmacies!
Every day families are faced with the heartbreaking news that their child has a serious, life-threatening condition, yet many do not know about or have access to palliative or hospice care. To raise awareness about the unique needs of children with life-threatening conditions and their families, the Children’s Hospice and Palliative Care Coalition, NHPCO, and the National Hospice Foundation launched a new campaign last month called Partnering for Children, with actor Melissa Gilbert as its national spokesperson (see our Q&A with Gilbert on page 46).

The goals of the Partnering for Children campaign are to:

- Increase awareness of the benefits of hospice and palliative care among care providers and the general public;
- Rally healthcare providers, policy makers, funders, members of the media, and other key stakeholders to advocate for quality care for children with life-threatening conditions;
- Mobilize parents, pediatric palliative care providers and communities to initiate community-based care and support systems for children and their families;
- Increase funding for pediatric palliative and hospice care initiatives, awareness activities, and advocacy efforts so that children with life-threatening conditions and their families have knowledge of and access to the care and support they need.

Through this campaign, a variety of materials are available, free of charge, for your use in helping to increase access:

- Community outreach materials and engagement strategies to engage parents and healthcare providers;
- National media and communication tools to publicize campaign activities, raise funds, and gain credibility—including PSAs, display ads, flyers, and news stories that feature campaign spokesperson Melissa Gilbert;
- Educational materials for parents, siblings and caregivers that cover a wide range of topics for pediatric care providers to use in all care settings;
- Plus, a “Virtual Resource Library”— an online catalog of “best practices” and educational resources that hospice and palliative care providers can use to create or enhance their care delivery to seriously-ill children and their families.

To access these resources—and other helpful information—visit partneringforchildren.org.

See page 48 to learn about Partnering for Children’s Memorial Bracelet Campaign.
Well-known actor Melissa Gilbert, who serves as board president of the Children’s Hospice and Palliative Care Coalition, talks about how she became involved in pediatric issues—and her new role as spokesperson for the new national campaign, Partnering for Children.

How and why did you become interested in pediatric issues?

It’s kind of a long story. I have, since I was a tiny girl, dealt with death. Or death has dealt with me. I lost my best friend, when we were four. I lost my Dad when I was 11. My first dog when I was 12. My great Aunt Mary when I was 13. Members of the “Little House” crew…it is no secret that the death of Michael Landon affected me deeply. The list of loss … my personal one goes on and on.

When I look back at my life, it’s also really amazing to me how, repeatedly, my path has crossed with that of a chronically or terminally ill child. I have this thing, whenever I visit someone in a hospital or if I am shooting in a hospital, I connect with the head of public relations there to see if there are any patients who might want to visit. Nine times out of 10... and this has gone on for decades, I end up on a pediatric oncology floor.

A few years ago, when I was the president of the Screen Actors Guild (SAG), I heard about a boy named Dustin Meraz. He was at Children’s Hospital Los Angeles (CHLA) and was dying. He wanted to be an actor. I was asked to give him a SAG card. Well, we got him his honorary card and we had a ceremony for him at CHLA. It was one of the best days of my presidency...maybe one of the most important of my life. Dusty died two weeks later. I wear his words on my wrist, “Today is a gift, have fun.” He’s right, you know.

I was asked back to CHLA for their annual holiday party for the kids on Dusty’s unit. That day changed the path of my life forever. That was the day that I was hit by the blonde tornado, Lori Butterworth, co-founder of the Children’s Hospice and Palliative Care Coalition. She asked for my help. She’s a tough woman to say no to actually, it’s impossible to say no to her; especially when she’s got you pinned up against a wall.

A little while later I had lunch with her and her co-founder Devon Dabbs. I listened to their stories in awe and horror, so moved by what they told me. So many statistics and case numbers and long-named diseases, but underneath all of that there is a child. A child who needs help. A child who may know that he/she is dying. That child has a family. That family needs help too. The medical costs alone are staggering. Not to mention the tremendous financial and emotional burden these families must carry.

I myself have a million dollar baby... that was what it cost to keep my son Michael alive for his first year. Michael was born prematurely. The first year of his life was... extraordinary. Like a war almost. Thank heaven for the SAG health plan! I look at him now, and I can’t believe he was ever so frail! Michael, who just started sixth grade, is responsible for giving me my motto, “Love, trust, hope, and believe.”

How did your experience as president of the Screen Actors Guild prepare you for your work with Children’s Hospice?

In addition to bringing Children’s Hospice into my life, my two terms as president of SAG helped me to further develop and hone my acumen for the workings of the business world. I worked with a variety of diverse stakeholders who had equally
diverse sets of interests. This experience taught me how to identify and leverage the best resources and direct those resources to the program that most needs the support. In turn, I have put this knowledge to work— together with Devon and Lori—at Children’s Hospice and now with NHPCO. I am honored to take these life experiences and make a difference for children and families across the country through the Partnering for Children campaign.

**What is your main goal for Partnering for Children?**

To get the word out and increase support for our shared vision. The best way to do this that I can think of is to tell our stories. We must make people aware of what it is like to care for a dying child with little or no support. These families need nurses, social workers, spiritual advisors, grief counselors, and volunteers to go do laundry... anything! Everything!

We know that many children who die in this country die in uncontrolled pain. Unnecessary pain because they don’t have access to hospice care when they need it. This is disgusting, frightening and wrong. We at Children’s Hospice aim to change that one child, one case at a time, until all children who need hospice and palliative care can get it and their families are not left to suffer alone. It is our great hope that working with NHPCO through the Partnering for Children campaign will get us even closer to our vision.

**What is your message to the professionals about pediatric palliative care (i.e. hospice, palliative care, coalition folks)?**

The words “children” and “hospice” should never go together, but unfortunately, they do. It is our collective responsibility to ensure the proper care and support for these children and their families. Honestly, I think you people are angels here on earth. My message is simply to keep up the good work and please do everything in your power to spread the word about the work of pediatric palliative and hospice care and Partnering for Children. Together I’m confident that we are a movement that cannot be stopped in bringing justice and care to those who most need our help.
Today is a gift… have fun!

Dustin was an actor at heart, and thanks to his friend Melissa Gilbert, he became an honorary member of the Screen Actors Guild. For Dustin, each day was an adventure and an opportunity to celebrate life. He loved his family and friends. He lived each day as a gift and taught us how important it is to have fun!

Only Love

The length of a life does not reflect the depth of the love shared between a parent and a child. The Only Love bracelets are in memory of Alexis Claire and the thousands of infants and children whose legacies remind us daily of the power of “only love.”

Live and Love It Up!

At age 7, when Mikaela heard the saying “Live it up” she replied, “No, you gotta live and love it up … because if you’re not loving, you’re not living.” Mikaela embraced each day with a smile and spread her message by leading her life with actions that spoke for themselves. They screamed “Live and Love it up!”

Dance … whenever, wherever, forever!

Dancing, singing, twirling, reading, telling stories; Maddy was the choreographer of her life, authentic with each step. She continues to beat within the rhythm of our hearts — we are so incredibly grateful for the dance.

Get in and get your hair wet!

Nick always knew that if you sit on the sidelines of life, too afraid to dive in, you would miss living. He inspired everyone he met never to give in to doubt and fear. Through his courage and humor, Nick reminded us not to worry about the silly stuff. Whenever life gives you the opportunity, you gotta … “Get in and get your hair wet.”
A Message from Children's Hospice and Palliative Care Coalition Board President
Melissa Gilbert — In a perfect world the words “Children” and “Hospice” would never go together, but unfortunately for many families, it is a painful reality. A few years ago, in my role as President of the Screen Actors Guild (SAG), I met a little boy named Dustin whose body was racked with cancer but had dreams of being an actor. It was an incredible honor for me to know Dustin and to present him with his honorary SAG card. When I said to him, “Dustin, it is now official. You are an actor!” his smile melted my heart. He told me to always remember that “Today is a gift... have fun.” From that moment, my life changed. Dustin died two weeks later.

Since that day, I have had the honor of getting to know so many children whose wisdom and courage inspire me daily. In their memory, we have created these bracelets which commemorate their poignant words of hope.

100% of the net proceeds goes directly to improving care and quality of life for children with life-threatening conditions.

Now, as President of the Board of Directors of Children’s Hospice and Palliative Care Coalition, I’m pleased that we have partnered with the National Hospice and Palliative Care Organization, the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. As it is aptly named, “Partnering for Children” — which includes our bracelet campaign — is raising awareness about the unique needs of children with life-threatening conditions and their families.

I hope you will join us in making sure that when a child has a serious illness, they have access to compassionate, family-centered care and that when a child dies, they live on in our hearts. To order a bracelet for yourself or as a meaningful gift, please visit www.childrenshospice.org or www.nhpc迎合.ORG/marketplace.

“Working with these children puts everything in perspective.”
— Mandy Moore

Children’s Hospice and Palliative Care Coalition thanks Jennifer Scarbrough of Zia Jewelry, www.ziajewelry.com, for the original design and production of these bracelets. Because of the generosity of everyone at Zia Designs, 100% of the net proceeds from the bracelets benefits children with life-threatening conditions and their families.

“I am honored to be associated with brave little Dustin by wearing this bracelet.”
— Johnny Depp
Winners of this year’s Hospice and Palliative Care Photography, Film and Writing Contest were just announced during NHPCO’s 8th Clinical Team Conference in late November. Here, we are proud to share the list of winners and the three first-place winning photographs. To view all the winning entries, please visit nhpco.org/awards—they are a wonderful testament to the talent and creativity of so many members around the country.

Winning Photos

Child Category

First Place:

Innocence

By Diane Schafer

VITAS Innovative Hospice Care®

Ft. Lauderdale, FL

Second Place:

Lean on Me

By Ben Fournier

Delaware Hospice

Wilmington, DE

Honorable Mention:

Connecting

By Becky Bahn

Hospice & Palliative Care of Cabarrus County

Kannapolis, NC

Untitled

By Roger Abraham

Total HomeCare and Hospice

Wichita, KS

Adult Category

First Place:

Golden Companions

By Rick Foster

Blue Ridge Hospice

Winchester, VA

Second Place:

Floßie Sees a Sunset

By Patricia Klein

LifePath Hospice and Palliative Care

Tampa, FL

Honorable Mention:

It’s About How You Live

By Candice Arana

Hospice of Southern Illinois

Belleville, IL

Generations

By Ashley Faison

Hospice & Community Care

Rock Hill, SC
**Nature Category**

**First Place:**
*Grief Light*
By Paul Mullinax  
Lincolnland Hospice of Sarah Bush  
Lincoln Health Center  
Mattoon, IL

**Second Place:**
*Quiet Time on the River*
By Marilyn Peck  
Gulfside Regional Hospice  
New Port Richey, FL

**Honorable Mention:**
*Autumn Passage*
By Carol Hutchison  
HospiceCare Inc.  
Madison, WI

**The Journey**
By Shannon Slater  
Hospice of the Carolina Foothills  
Columbus, NC

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**Winning Films**

**First Place:**
*203 Days*
By Bailey Barash  
The Weinstein Hospice  
Atlanta, GA

**Second Place:**
*Comfort*
By Ashley Faison and Maureen Isern  
Hospice & Community Care  
Rock Hill, SC

**Honorable Mention:**
*Making a Difference in a Child’s Life*
By Terry Murphy  
Providence Hospice of Seattle  
Seattle, WA

*Finding Strength, Taking Comfort: One Family’s Story*
By Maria T. Roesler  
Saint Barnabas Hospice and Palliative Care Center  
West Orange, NJ

*Camp Healing Powers*
By Alan Fraser  
Community Hospice of Northeast Florida  
Jacksonville, FL

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**Winning Essays**

**First Place:**
*La Vida Lessons*
By Elizabeth Vega  
Mesilla Valley Hospice  
Las Cruces, NM

**Second Place:**
*Love Without Words*
By Ruth Hancock  
VITAS Innovative Hospice Care®  
Dallas, TX

**Honorable Mention:**
*Zeb’s Apples*
By G. Leigh Wilkerson  
Circle of Life Hospice and Palliative Care  
Springdale, AR

*The Winter of Grief*
By Stephanie Stevens  
St. Mary’s Hospice and Palliative Care  
Grand Rapids, MN

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**Winning Poems**

**First Place:**
*Turning to Go*
By G. Leigh Wilkerson  
Circle of Life Hospice and Palliative Care  
Springdale, AR

**Second Place:**
*Sisters 2*
By Earl Beshears  
Delaware Hospice  
Wilmington, DE

**Honorable Mention:**
*The Winter of Grief*
By Stephanie Stevens  
St. Mary’s Hospice and Palliative Care  
Grand Rapids, MN

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  - An evaluation of hospice software systems
- **Benchmarking Issue** (Winter Edition)
  - The industry by the numbers
- **Process/Regulatory Issue** (Spring Edition)
- **Compensation Issue** (Summer Edition)
  - What and how are hospice staff being paid

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Leadership
For nearly 30 years, VITAS has been a leader in the American hospice movement, helping to define the standards of care for hospice and working to ensure that terminally ill patients and their families have ready access to compassionate and effective end-of-life support.

Advocacy
As a pioneer in the hospice movement and an advocate for the rights of the terminally ill, VITAS has been a leader in expanding hospice access to population groups historically underserved by healthcare providers... fulfilling our mission to offer all who are battling a life-limiting illness the opportunity to benefit from hospice care.

Growth
VITAS is committed to expanding the reach of its hospice services, bringing its unique brand of Innovative Hospice Care® to growing numbers of hospice-appropriate patients. As of July 2007, VITAS was caring for more than 11,000 patients and their families each day, with more than 8,700 employees at 43 hospice programs in 16 states.

Commitment
Our organization is committed to giving back to the communities we serve, through partnerships with organizations such as the National Hospice & Palliative Care Organization, Rainbow/PUSH Coalition, Duke Institute on Care at the End of Life and Foundation for End-of-Life Care.

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- Strategic Audits
- The Watchman™ Program — The First Hospice Specific Faith-Based Marketing Strategy.
Diane Schafer, a volunteer photographer for VITAS Innovative Hospice Care® in Fort Lauderdale, Florida, captures the special bond between sisters in this winning entry from our 2007 photography contest. “What touched me most,” Diane said, “was how the big sister didn’t notice her younger sister’s tubes, or her epilepsy—but simply played with her without all the innocence of a child.”

This photo won first place in the contest’s “Child Category.” See page 50 for all the winning entries.