



E-NEWS

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Issue Topic: Complementary Therapies in Pediatric Palliative Care, part 1

(1 of 2 issues looking at this topic)

Welcome to the seventeenth issue of the ChiPPS electronic newsletter. This issue of our e-newsletter addresses a variety of examples of the use of complementary therapies in pediatric palliative care. The articles in this issue describe some experiences of family members in this area, as well as views of professional contributors who address various types of complementary therapies in pediatric palliative care. Here you will find links to a PDF collection of articles on these topics.

Please note that we have come across so many topics and contributors related to complementary therapies and their connections with pediatric palliative care, that we have decided this will be the first of two issues in this topical area.

This newsletter is produced by ChiPPS (the Children's Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO's Communications Work Group, co-chaired by Christy Torkildson and Maureen Horgan.

Comments about the activities of ChiPPS, its Communications Work Group, or this issue of the newsletter are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues of this newsletter. Please contact Christy at torkc@sbcglobal.net or Maureen at Maureen.Horgan@providence.org.



Issue #17: Complementary Therapies in Pediatric Palliative Care, part 1

(Click on the "bookmark" tab on the left-hand side of the PDF document for links to the following articles.)

Reflections on a "Dream" Vacation

p. 3

Joan Kast, MSW, and Peter Stephens, MDiv

The authors provide reflections on one family's "dream come true...the trip of a lifetime." The wish trip they describe provided lifelong memories for a family with three boys living with Duchenne's Muscular Dystrophy. (Please note that many organizations may help to fulfill the wishes of ill children and their families in similar ways. You can search for such organizations locally, regionally, nationally, and through independent foundations.)

Hippo Who?!!

p. 4

Claire Vesely, RN, BSN

Claire is a pediatric nurse and volunteer who works with her horse and pony teams. In this article, she invites the reader to discover how "hippotherapy" provides both physical and emotional benefits in the pediatric palliative care setting. Through case examples and beautiful pictures she vividly and humorously describes the benefits of incorporating horses and ponies into the lives of seriously ill children.

Dreamwork as Spiritual Care for Dying Children and Their Families

p. 8

Beverly Isley-Landreth MDiv, ThM, CHTP

The author demonstrates how dreamwork can be an important tool in the spiritual care of parents, siblings, and the seriously ill child. She shares specific principles of dreamwork and techniques to support children and families in exploring nightmares and numinous dreams. This deeply spiritual and creative work supports meaning making, finding hope, and feeling safe.

Confessions and Musings of a Reluctant Reiki Master

p. 13

Rev. Karen B. Taliesin, BCC

A hospital chaplain humbly and honestly writes of her experience providing comfort and support through Reiki. She notes that "there is healing that may never show itself in a way we can comprehend." Capturing the essence of a healing technique that is not easily understood or described, she writes about a therapy that has provided support and comfort to adults and children for over a century.

Playing at the Threshold: The Role of the Therapeutic Clown in the Care of Children with Life-Threatening Illnesses and Their Families

p. 16

Camilla Gryski, M.L.S., M.Ed.

Camilla, who also dons the character of Flora, supports children in her role as a therapeutic clown. She provides the reader with a comprehensive overview of the therapeutic clown's role on the pediatric palliative care interdisciplinary team. You will discover how the therapeutic clown creates a safe environment, empowers children, invites play and the "expression of the inexpressible."

Use of Positive Images as a Spiritual Intervention

p. 21

Rev. Nayer Taheri, MASC

Reverend Taheri provides a framework for using projected image slide shows to provide comfort, relaxation, and the invitation to explore meaning in the experience of living and dying. She acknowledges the limitation of words and the potential power of images in the care of children and the entire family. Case studies and a step-by-step planning guide provide an overview of how you might incorporate this intervention into your practice.

My.NHPCO

p. 22

Jon Radulovic, MA

My.NHPCO is the new social networking site created expressly for members of NHPCO. It promises to be a valuable tool for those involved with ChiPPS. This article outlines some of the key benefits.

Items of Interest

p. 25

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

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REFLECTIONS ON A "DREAM" VACATION

Joan Kast, MSW

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Members, Daniel's Care Pediatric Team

Hospice of the Bluegrass

In August of 2001, the Dream Factory helped a dream come true for the Thornsburg family in Kentucky. That summer, the three "Berry boys" accompanied their mother, sister, and other family members on the trip of a lifetime to Disneyworld in Florida. The royal treatment began with a surprise limousine ride to the airport and a first-ever plane flight, and continued with the outstanding arrangements awaiting them at Give Kids the World village.

Now, eight years later, when Willie and his mother, Betty, share their still-vivid memories, their faces light up with joy. What makes these recollections particularly poignant is the fact that two of the boys, and the uncle that shared this experience with them, are gone now ... the boys' lives have been taken by the same disease (Duchennes Muscular Dystrophy) that will someday take the youngest, Willie.

Age 8 at the time, Willie's favorite memories of Disneyworld include an encounter with Cinderella, a beautiful princess who called him a doll, told him "you've got the prettiest eyes, the color of my dress," and said she wanted to take him home with her! Willie also recalls meeting Tigger, who pantomimed taking Mom with him; in response, Willie shook his head and informed Tigger that Mom was "mine." Most memorable for Willie in the village itself were – wait for it – the talking garbage cans, which he kept quite busy, and vocal, by offering to throw lots of garbage away! During a side trip to Daytona Beach in the van provided by the Dream Factory, when Willie's older sister asked which beach they were going to, Willie proudly informed her that he knew the answer – they were heading to "Beethoven Beach."

Mom speaks about the pleasure of sharing this time with her family, of having their own cottage to stay in, with everything they could want including 3 bedrooms, 2 bathrooms, and a whirlpool too that they all enjoyed. She fondly recalls watching her children experience the sheer joy of Disneyworld and having all their needs catered to in the village (including a pool with a rolling chair, so that these wheelchair-bound boys could make a big splash on those hot days!) ... another world from their everyday lives that were so often filled with the struggle to just meet everyone's basic needs.

Mom also talks about her deceased sons' favorite times there; for Michael, it was the train that took them throughout the Magic Kingdom. And Jesse just couldn't get enough of the ice cream parlors! Of course, there was plenty of great food available for the whole Thornsburg clan, night and day (including their cottage being stocked with their favorite snacks and soft drinks).

As the sharing of these memories came to a close and we ended our visit, we saw the light of joy still in Willie's and Betty's eyes. We are so grateful this family was given the gift of being together for this magical experience. Thank you to the Dream Factory and all who made it possible.

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“HIPPO WHO?!!”

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Wallowing in mud, cooling off in the water whilst swatting away flies and foraging through vegetation, hippos can lead a very labile life in the heart of Africa. When presented with the word “hippotherapy” all kinds of images like those previously alluded to come to mind but not that of a horse! Hippotherapy is the proper term given to the use of horses and ponies as a therapy treatment tool. The derivative of hippotherapy, or “treatment with the help of a horse,” comes from the Greek root of the word “hippos” or horse (www.americanhippotherapyassociation.org, 2007). Hippotherapy encompasses many treatment domains: physical, occupational, speech and language. Because of this the benefits of this treatment modality are far reaching (see Table 1).

Table 1: Benefits of Hippotherapy and Therapeutic Horseback Riding

Physical	Improved balance and equilibrium
	Improved coordination
	Improved head and trunk control
	Improved postural alignment
	Normalization of tone
Psychological	Improved self esteem
Physiological	Positive effect on respiration and circulation
	Positive effect on bowel and bladder
Sensory and Motor	Provides strong graded tactile, proprioceptive and vestibular input
	Improved motor planning, bilateral coordination and spatial awareness

Source: www.mtrpinc.org/benefits

Hippotherapy has largely been used with children including those with physical conditions such as cerebral palsy, post-stroke or traumatic brain injury, arthritis, and genetic syndromes. It is the gentle rhythmic movement of a walking horse that replicates the pelvic patterns when a human walks. The horse and rider become one and a child will alter his or her own muscle tone, balance, and coordination to respond to the changes in the motion of the horse. The result is an improved posture and tone which translates to improvement in other gross motor skills, such as sitting, walking, or weight bearing and balance (www.aetna.com, 3/31/07). As an example, for one young rider, riding the horse also meant he could learn how to rope a cow:

In addition, the unspoken psychological benefits of hippotherapy mean children with disorders such as autism, Asperger’s syndrome, self-esteem challenges, learning disabilities, and speech-language disorders also benefit. The reason can be attributed to an unconditional level of trust that develops between the child and his or her equine partner that only has positive effects on a child. Parents who once described their child as someone who previously showed little interest in life, now describe that child as looking forward to riding lessons, being ready ahead of time for a lesson, and opening up



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communication with friends and family. Children previously trapped in their non-communicative world have been known to utter their first words whilst working with a horse, either on the ground or in the saddle.

Personally, both as a volunteer with SonRise Equestrian Foundation, and as a nurse working at a special pediatric inpatient facility called George Mark Children's House, I have witnessed two organizations merge their missions in a truly extraordinary way.

Hippotherapy is not limited to the riding itself, it also has a second purpose as pet therapy because the benefits of a horse reach beyond just riding, particularly if the horse is small! Two miniature horses, Blackie and Joey, have recently been given a new role in life as pet therapy horses. These pintsize animals are taken into medical facilities to the bedside, to meet, greet, and love children who are unable to leave their medical home. Please enjoy the following true story which illustrates this unique therapy.



The Tail of Two Mini's

Once upon a time there were two brothers, named Mark and George. They both lived life as much as possible until, as young adults, they left this world—one from a tragic car accident and the other after a short battle with cancer. Their caring and dedicated sister, Kathy, took it upon herself to remember her brothers in a special way. Her mission, along with that of another incredible doctor named Barbara, became to open a very special house. A house that would be home to children with life-limiting illnesses and their families, a house to provide a source of comfort in times of difficult circumstances. In March 2004, George Mark Children's House opened in San Leandro, California. It became the first freestanding respite and end of life care facility for children in the U.S.

"Just above the tree line, a lone pine clung to the mountain. Naked it stood to the ravages of nature. Its gnarled roots thirstily thrust down. In their desperate struggle to live, they pried cracks in the rocks." (Fulgaro, 1994, p. 11)

As with the pine tree, children with these conditions struggle to live. But, they are still children, children who love to play, smile, and simply "be" in spite of the odds. Which is why two little miniature horses (minis) named Blackie and Joey, of SonRise Equestrian Foundation, arrived at George Mark Children's House. These four-legged bundles of fluff, fur, and fun have ensured the play and smiles in the children at the House. Tentatively, but with innate care and sensitivity, Blackie and Joey met the needs of these children and their families.



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National Hospice and Palliative Care Organization



From bringing up the rear of the musical Halloween parade led by a Pied Piper to waiting patiently whilst they have been groomed over and over, these minis have given unselfishly. On numerous occasions they



have been there at the most difficult of times. For one little girl, riding on Blackie was the last thing she did before going to Heaven. For a sibling, the ponies got there just in time as he had lost his baby brother minutes earlier. Another child lay in bed unresponsive but when her Mum whispered to her that Blackie had come to visit her especially, she opened her eyes and said 'horse!'—her last word before she died. When her family later returned to the House they made a commemorative tile with their daughter's and Blackie's picture on it.

And it is not all at sad times either. For Mei Mei, a "frequent flyer" at George Mark Children's House, meeting the minis provided something brand new. Between visiting the home where the minis lived and seeing them at the House, Mei Mei always looks forward to seeing her friends. Blackie trots willingly behind Mei Mei as she speeds along in her electric wheelchair. He let her bathe him while she whizzed around him and lathered him up into a sudsy bubble. Mei Mei ingeniously squeezed out the water and soap in the sponge with her wheels—a new method indeed! And the piece de resistance, Mei Mei who has been in a wheelchair since she was a child was able to ride Blackie, around and around and around.

One child exclaimed, "A horse does not belong in a house!" yet another was excited when Blackie pooped in his bedroom—now he wasn't the *only* one who had accidents. Even teenagers soften in the presence of animals. Manny had grown up in the Mexican countryside but found himself hospitalized in San Francisco for a whole year. His one wish was to see green grass, to be outside, and to be around animals, especially horses. Manny came to George Mark Children's House along with his stuffed horse Café de Leche who was white with brown patches and spent time with Blackie in his room.





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National Hospice and Palliative Care
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Have you ever received a hug from a horse? It is an amazing thing. Both minis have instinctively given these to the children who are not able to speak or do for themselves, a secret communication that is unique and unconditional. The peace and comfort we see on the faces of these children is immeasurable.



References:

Fulguro E, *The Tree: A Little Book of Faith and Hope*, Holy Spirit Press, 1994.

www.aetna.com/cpb/medical/data

www.americanhippotherapyassociation.org

www.cerebralpalsy.org/treatments/hippotherapy.html

www.mtrpinc.org/benefits.html

www.sonriseequestrianfoundation.org (all photos courtesy of SonRise Equestrian Foundation).

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DREAMWORK AS SPIRITUAL CARE FOR DYING CHILDREN AND THEIR FAMILIES

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It has been my experience that extraordinary dreams, series of dreams, and interconnected dreams frequently occur around dying children and their families. People tend to be mystified by the intense dreams they experience during this time and often react to the invitation to talk about their dreams like a drowning person when thrown a life-line. It is sometimes hard to find someone who will listen to arresting or disturbing dreams without dismissing them as the product of "too much pizza." For these children and their families, intense dreams during this process can leave them with a haunting sense of something left undone, something left unattended they are unable to shake off or release. And almost inevitably there will be the appearance of giants and monsters, bursting on the scene in these dreams, in terrifying ways.

Dreams that come in the midst of end-of-life transitions can stand as sentinel events for any individual taking the long view across his or her lifetime. Particularly however, for dying children and their families, dreams that emerge during this time mark important junctures in the journey and are almost inevitably charged with immense spiritual energy. This is true for both the nightmare and the numinous dream...both are spiritually powerful experiences.

I have approached dreamwork from a Jungian perspective, which helped me form the technique that I use with children outlined in this article. You will find below the basic outline of this technique and a listing of resources for further reading. You also will find a brief description of key dreams from families that speak eloquently to the many ways that giants and monsters can appear in dreamscapes, and to this deep need to tell the story of their dreams, and to feel they are being heard.

Dreamwork can be an important tool in spiritual care for parents, siblings, and the dying child, because it provides an avenue for resolution of the core spiritual tasks (to make meaning and to find hope):

- during illness
- at the time of death
- and during bereavement

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 repeatedly heard in the dreams of dying children and families 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." (p. 213)

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), the monster Grendel; 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." (Cirlot, p. 213)



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 dashing to the safe place, 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 3 “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 or her safe, i.e., swords, flashlights, ropes, lanterns, parachutes, wings, etc.

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, move through time, etc. 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, 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.

Dream: 7 yr old with cancer, 4 months before death: “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.” This child chose a “sword made of light” as her power tool.

The guide asked to talk with the monster, and the child answered 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 asked the child to suggest something else for the monster to eat. Then the guide instructed the monster that it could not return to scare again. The child showed the power tool to the monster, saying it would keep her safe. The monster stayed outside the impenetrable bubble/shield at all times. The guide assured the child the power tool was always with her; if she called for the tool it would appear.

The Pathway Out

The way out engages the same sights, sounds, 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?" Give "high 5's," do a "victory dance."

Read carefully the following dreams of different family members as they struggled with the profound challenges of the dying process. Notice the different ways giants and monsters present in these dreams.

Nightmare of a Parent

"I saw my son lying on a wooden slab...he was trapped inside the shell of a beetle...he was crying and begging me to help him get out."

- *8 yr old with a degenerative neurological disorder –
had been unable to communicate for about two years

Nightmare of a Sibling

"There was a giant in the middle of the playground. He was so big, he took up too much room, so nobody could play. I was at the top of the slide, but I was scared to come down...I thought he might step on me and squish me, or he might eat me up."

-*6 yr old sibling of a dying toddler

Nightmare of a Dying Child

"I was playing in my backyard and I heard my mother, so I ran into the back door into the kitchen. There was a big green monster with big teeth standing in the middle of the floor, and his tail was swishing back and forth. My mother came out of her bedroom and we were screaming trying to get to each other, but we couldn't get past the monster."

- *7 yr old with brain stem tumor...1 mo. before her death

Notice the energy present in each of these dreams, and how clearly we can see family members trying to actively tackle issues related to core spiritual tasks.

In addition to the Nightmare, the **Numinous dream** was also very common among families with whom I worked. These are "Big" dreams, charged with distinct spiritual energy. I worked with these dreams in much the same way as with the nightmare. It remained essential for the dreams to be processed in creative, age-appropriate ways. The technique just described can be adjusted to accommodate the child's developmental levels.

Parent's Numinous Dream

- * **Parent of 7 yr old with a brain tumor...1 week after death**

"I saw my daughter lying in a coffin. I moved closer to touch her...she opened her eyes, sat up, jumped out of the coffin looking well and beautiful. She smoothed down her ballerina length white



dress, showed me she had on white tap shoes, and said, 'see Mama, I'm fine', and then she began to dance".

Child's Numinous Dream

-* 9 yr old, 1 week before death

"I saw a beautiful flower garden full of purple flowers...I knew this was God's flower garden, and I was one of the flowers, and he was about to pick me for his table."

Providing the Framework For Working with the Numinous Dream

- **The Doorway** and **Guide** are the same
- **The Power Tools** are different:
 - For the flower garden, the tool was a beautiful glass vase with water in it
- **The Vehicle** remains the same
 - The impenetrable bubble or shield

- Engage the ritual to "grow" the bubble around the child, the guide, and any others present
- Have "hand controls" for maneuvering the vehicle
- **Be prepared for the child to choose to "step out" of the vehicle at some point in the journey when working with the numinous** – the guide can step out with the child, i.e., "walking" through the flower garden
- **The Story**
 - Engage the Senses
 - Sights, sounds, smells, tastes, textures
 - Keep "Safe Place" Buttons handy
- **The Interventions**
 - when the messenger or scene appears, ask what the child wishes to do
 - "play" the intervention
 - The guide asks to talk with messengers, angels, animals, etc. and the child answers the questions
 - Q. "what do you see?", "what do you hear?"
 - A. "purple flowers everywhere", "I hear birds singing"
 - Q. "why have they come in your dream?"
 - A. "so I won't be afraid"
 - Q. "where are we?"
 - A. "God's flower garden"
 - The guide invites the child to ask questions

The Way Out is the Way In

- **The pathway out engages the same sights, sounds, smells as the narrative of the journey in.**
- Use ritual or ceremony to dissolve the bubble/shield
- "Debrief" the child and family
 - Encourage family dialogue
 - Engage around their sacred story (the faith tradition or spirituality that has meaning for the family – frame the numinous dream within their faith or spiritual context)

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.

Cirlot, J. E. (1995). *A Dictionary of Symbols* (2nd ed.). New York: Barnes & Noble Books.



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Further Reading:

- Marc Ian Barasch, *Healing Dreams*, 2000, New York: Riverhead Books.
- Joseph Campbell, *The Hero With A Thousand Faces*, 1949, New York: MJF Books.
- J.E. Cirlot, *A Dictionary of Symbols*, 2nd ed., 1971, New York: Barnes and Noble.
- Clarissa Pinkola Estes, *Women Who Run With the Wolves*, 1995, New York: Ballantine Books.
- C.G. Jung, *Children's Dreams*, 2008, Princeton: Princeton University Press.
- Jeremy Taylor, *Where People Fly and Water Runs Uphill*, 1993, New York: Warner Books, Inc.
- Marie-Louise von Franz, *On Dreams and Death*, 1998, Peru, IL: Carus Publishing Company.

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CONFESSIONS AND MUSINGS OF A RELUCTANT REIKI MASTER

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Confessions

The message on the Pastoral and Spiritual Care referral line was from a nurse stating that the family of 8-month-old Ben [all names of patients in this article have been changed] was requesting Reiki. I entered the patient's room and introduced myself to his mother and grandmother, then asked if they were familiar with Reiki. "We've heard of it," his mother said, "and think it might help Ben. He's been so agitated today." We talked a bit more about Reiki, Ben, and his congenital condition that brought him to the hospital periodically, and then I turned to Ben who was sleeping somewhat fitfully in the crib. Grounding myself, I said a silent prayer of intention as I mentally recalled the Reiki symbols, and then began with my hands positioned just above but not touching his head. For the next 15 minutes keeping my hands about an inch above his body, I used Reiki hand positions as I worked my way down to Ben's feet. When I was finished, both Ben's mother and grandmother were staring at one of the monitors, saying, "That's the best those numbers have looked all day, and he's definitely more relaxed. Can you come back tomorrow?"

I was paged by a nurse on the NICU asking me if I thought Reiki could help 3-week-old Olivia who was born with a life-threatening heart malformation. Both of her parents were in the room when I arrived and though they had never heard of Reiki, they told me they were willing "to try anything to make her more comfortable." I spent about 10 minutes providing Reiki to this little one when I saw the parents looking over my head at the monitors and smiling. "It looks like she really likes this—those numbers look better than they have in a while," her dad told me, adding, "What did you call it?" I left some information on Reiki with them and went back almost daily until her death three weeks later.

I had received a referral from a family who had requested Reiki for their 11-year-old son, Kyle, the day after he had had back surgery. When I arrived on the PICU, Kyle was quite anxious and had been crying. His mother was by the bed, holding his hand and trying to soothe him. I introduced myself and asked if they had requested Reiki. She looked relieved as she said, "Yes. I've had a couple of Reiki treatments in the past and really enjoyed them." I asked Kyle if he knew anything about Reiki and he said tearfully, "No." I decided this was not the time for "Reiki 101," yet I did not want to agitate him further by placing my hands above his body without him knowing what I was doing. So I switched gears and asked him where he liked to go to have fun. Somewhat taken aback, Kyle looked at me and said, "The beach...I guess." I then began to quietly talk about the beach, how sunny and warm it was, and how I could almost feel the warm sand under my feet. Kyle's shoulders relaxed, he settled back into the bed, and asked if this was a "warm water beach like they have in Florida." I assured him that the water was just right for swimming and told him about the sand castle I was building. One of the nurses walked behind me, squeezed my arm, and whispered, "Keep it up—his blood pressure is much better!" As he began to relax more, I asked Kyle if he could tell me what he was doing on the beach and he replied he was looking for shells. After a bit, Kyle said, "I like this Reiki—I like it a lot!" I hadn't the heart to explain to him at the time that what we were doing wasn't Reiki but during the next week as Kyle recovered in the hospital, I was able to offer him several actual Reiki sessions. Before he was discharged, Kyle told me, "I liked your Reiki okay but I *really* liked going to the beach with you!"

A social worker stopped me on the medical unit one afternoon and asked if I had met 6-year-old Stephanie and her grandmother yet. I wasn't familiar with the patient so the social worker explained that Stephanie was being raised by her grandmother as her mother was not involved due to addiction and



abuse issues. Stephanie had just been diagnosed with a very aggressive cancer and the social worker felt the grandmother could use all the support she could get. I stepped into the room and introduced myself as one of the chaplains. The grandmother said she was glad to meet me and that Stephanie was in pain, which the medical team was having a hard time managing. Though her grandmother tried holding her, talking with her, and distracting her with toys, Stephanie continued to be restless and agitated. Together, we tried singing and playing with her but nothing helped. Stephanie's grandmother was growing more and more frustrated so I asked, "Have you ever heard of Reiki?" The grandmother looked at me horrified and said, "That's the work of Satan!" Immediately I began to apologize when the grandmother interrupted me saying, "But she could use a laying on of hands." So we laid our hands on Stephanie's little body and prayed for her comfort, beseeching God, Jesus, and the Holy Spirit to bring her peace. After quite a few minutes of prayer during which the grandmother cried and spoke of her grief for Stephanie's mother, Stephanie became quiet, even serene, and fell into a deep sleep.

I was paged to the room of an infant born prematurely. When I arrived on the unit, one of the nurses said, "I'm glad you're here. I told the mom about you and she wasn't so interested in the chaplain part. But when I said you knew Reiki, she wanted to meet you right away." Another nurse walked by and said lightheartedly with a smile, "Uh-oh, Church Lady is here to do her 'woo-woo' stuff!" We all laughed—these are exceptional nurses whose humor I always enjoy. In the room, the patient's mom was by the small crib holding her tiny daughter's hand. The mom knew quite a bit about Reiki and had had several Reiki sessions herself. I gave her daughter about a 15-minute Reiki session during which I saw the numbers on the monitors change somewhat. After assuring the patient's mom that I would return the next day, I walked out of the room to find the two nurses standing just outside the door. "We want to know how you do that," one of them asked. The one who had teased me earlier said, "Yeah, I give you a hard time about that stuff but it's pretty amazing. Do you know how much better she's doing now than before you went in there?"

Musings

Before I continue, I need to give my "working definition" of Reiki that very briefly describes this energy-based therapy. Reiki is a healing technique developed in the late 1800's in Kyoto, Japan, by Mikao Usui, a Japanese educator. Meaning "universal life force energy"—the life force energy that surrounds and interpenetrates all of creation—Reiki balances, energizes, and harmonizes all systems in the body by reducing pain and stress as well as promoting natural self-healing. Healing in a Reiki session is done with hands on or near the body and is determined by the recipient. The power for healing lies within the individual as Reiki energy is drawn through the practitioner by the recipient's cells. The Reiki practitioner's own energy is not used as the practitioner acts as a conduit for the energy. No faith or belief is required to give or receive Reiki, and it may complement and enhance all other forms of healing.

I took my first Level I Reiki course in 1988 and have progressed throughout the years to Reiki Master. Along with Reiki, I have also extensively studied shamanic and indigenous healing methods and rituals, visualization and guided imagery techniques, and have taken basic levels of both Healing Touch and Therapeutic Touch. I have also practiced daily meditation for 36 years (my family learned and started practicing meditation when I was 15-years-old) and highly value mindfulness as a healthy and healing way of life.

Part of the reason why I have spent much of my life studying so many different ways of "laying on hands" and other forms of healing is that at one point I felt I needed clarification as to the difference between the various methods and techniques. So I must be honest in relating that the energy therapy I practice now is probably best described as a blend of "all of the above." I completely respect each method and understand that some practitioners feel the purity of the technique is vital to its success. However as I bend over a child and place my hands just above this precious being's head, who's to say what is really at work here? Over the more than 20 years that I've been involved in energy therapies, I've seen miracles of



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all kinds including those where the heart rate slows from its too-rapid rhythm and the chest eases as the breath becomes less labored to those where the life struggling within a body gives way to Light and a more intangible form of love. Who's to say what's at work here? Was it the mental recollection of the Reiki symbols before placing my hands just so over the patient's head? Was it "Reiki energy" or the Holy Spirit? Was it the more focused attention in the room on the patient? Or was it simply my prayer of intention before I even entered the room, or the surge of hope from parents who are tired of seeing their child in pain?

Often when I am offering Reiki to a little one, I will invite the parents to join me. As I show them how to place their hands on or just above their child's body, I ask them to simply imagine being a conduit for gentle, healing love and energy. Parents are often surprised at how good this feels to them and to their child—though I strongly believe they do this very thing every time they lovingly touch their child.

I have a colleague who is practically unflappable and whose gentle presence is a constant comfort to us all. He is in his 70s and has been a chaplain at the hospital for over 25 years. Without taking a single course in Reiki, Healing Touch, or Therapeutic Touch, I think this chaplain is a conduit for profound healing energy (though his humility and deep faith prevents him from ever mentioning it). Simply by showing up, this man provides healing through his deeply tranquil and compassionate presence.

I know there is some amount of research on Reiki and other complementary and integrative healing methods that shows the benefits of energy-based therapies. But after over 20 years of being involved with hospice and hospital patients, my experience has been that there is often very little rhyme or reason as to why some patients seem to respond to Reiki (or HT, TT, laying on of hands, etc.) and others do not. Though I highly respect and revere Reiki, Healing Touch, and Therapeutic Touch along with other energy therapies as well as the traditions, masters, and teachers from which they continue to evolve, I wince internally when someone asks me, "How does it work?" I am, quite honestly, a rather reluctant Reiki Master. Because the more I practice the different methodologies—whether I blend them or attempt to retain the purity of a particular technique—the more I experience the profound subtlety and indiscriminate nature of "healing." For there is healing that may never show itself in a way we can comprehend, causing some to wonder why I bother to waste a patient's time with daily Reiki sessions. And then there is healing the result of which is dramatic, observable improvements that can be measured, charted, and celebrated. Whether it's subtle or dramatic, whether it comes from the loving touch of a mother's hand or from a compassionate presence, I've ceased trying to explain it.

So when asked, "How did you do that?" my answer is that I don't know, and whatever happened may or may not have anything to do with Reiki. I am always happy to respond to a referral for Reiki and I take my Reiki training and experience very seriously. But my experience of healing is that it is a continuously shifting concept, and often looks much different than what we had expected or hoped for.

Recently, I was in the room of 7-year-old Maddie who had been enjoying the Reiki sessions I had been providing her for a couple of weeks. Her mother liked to participate by standing on the opposite side of the bed and mirroring my hands as we worked down from Maddie's head to her feet. As we were finishing, Maddie's mom said, "She's always so much more relaxed after Reiki—it's making such a difference!" Maddie smiled and said, "It's because you have rain hands." Her mom and I looked at each other and said, "Rain hands?" "Yeah," Maddie responded, "Your hands rain love." Is it Reiki? Is it love? As one of my mentors is fond of saying, "It is what it is." May it be so.

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**PLAYING AT THE THRESHOLD:
THE ROLE OF THE THERAPEUTIC CLOWN IN THE CARE OF CHILDREN
WITH LIFE-THREATENING ILLNESSES AND THEIR FAMILIES**

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There are references to two clown characters in this article, both of them created by the author of this piece. Posy was the therapeutic clown for the Hematology/Oncology Program at SickKids for nine years. Flora is currently the therapeutic clown for the Palliative and Bereavement Care Service, at SickKids in Toronto.

What is a Therapeutic Clown?

The clown may be an unexpected presence in the health care setting, but historically and culturally, from medieval jesters to the sacred clowns of many First Nations peoples, clowns have been associated with healing and the well-being of society.

The Canadian Association of Therapeutic Clowns/L'Association Canadienne des clowns thérapeutiques (www.therapeuticclowns.ca) defines a therapeutic clown as a clown who is specifically trained to work in the health care field. The therapeutic clown is committed to being a regular presence in the health care setting, collaborates routinely with other members of the health care team, engages in on-going training and development, and receives appropriate remuneration for the work. All CATC/ACCT members agree to abide by the association's Statement of Principles and Code of Ethics. Therapeutic clowns hold true to the central ideas of clowning, but at the same time function as health care professionals. Their make-up is generally light, and their costumes are designed to be practical and appropriate to the settings in which they work. Therapeutic clowns are sensitive to the reactions of those around them, and are skilled at engaging children and their families. They are responsible and accountable for their actions, and may be required to offer feedback on their interactions in meetings, at rounds, and more formally through progress notes.

When the therapeutic clown works and plays in the area of pediatric palliative care – whether in a hospital, hospice, or home setting – her understanding of her work, the role she plays in the care of the child and family, her sensitivity and compassion, and indeed her sense of accountability and responsibility are heightened. Interactions with children, siblings, and other family members can be both intense and delicate. The support of a multidisciplinary team is essential.

The landscape of pediatric palliative care appropriately includes an emphasis on the child and family's quality of life. The nature of this care is holistic, encompassing physical, psychological, social, and spiritual wellbeing (Liben, 2008). The health care team must be responsive to each family's needs and to the unique nature of each family's journey with their child's life-threatening condition and ultimate death.

What Do Parents Want?

In an article by Beverly Antle, et al. (2005), "*Pediatric Palliative Care: What do Parents Want?*" the authors summarize the results of three qualitative studies done at SickKids in Toronto with families of life-threatened children. Four key themes emerged: respect for the child and family, greater co-ordination of services, normalization of the child's activities, and a focus on hope. The study participants suggested that energies could be better directed toward enhancing a child's quality of life and happiness rather than



trying to sort out information and services provided by different health care professionals. One parent commented "He just wants to be a seven-year-old-kid and do armspits and all that stuff." As one member of the multidisciplinary team that cares for these families, the therapeutic clown can offer interludes of play and laughter. She encourages in the child a sense of mastery and works to build a supportive relationship with the child and family.

Supportive Relationships

In many ways, the clown is well-suited to be a companion for the child on a journey with a life-threatening illness. The famous clown Grock (in Cline, 1983) described himself as being "as sensitive as a mimosa plant," with all his self-protective armor peeled away (p. 46). The vulnerability of the clown engages the child and helps to build a supportive relationship. Because the clown is an unexpected presence in the hospital, as out-of-place in the healthcare setting as the child, they can become allies. When the clown visits the child in the community, the tables are turned, but the clown is still not on home ground. Barbara Sourkes (1995) suggests that the establishment of "a secure therapeutic alliance" (p. 11) is an intervention in and of itself. This special alliance or relationship is frequently understood and appreciated by families. Once, to the delight of all the listeners in the playroom, a petite three-year-old greeted me by saying, "Hello, little Posy, Posy," even though I am obviously adult-sized. When – out of character – I attended the visitation of a child I had known for several years, I was introduced by his father as "a personal friend" of his son. Another parent commented as I arrived for her son's funeral: "He always let you in."

The therapeutic clown also works to build relationships with siblings, often creating opportunities for interactions with their brother or sister who is ill. Two sisters of a two-year old with a brain tumor who can no longer take part in the play, still love to sing to him the familiar songs Flora sang to him earlier on. With puppets on our hands, we sing about elephants, frogs, and teddies on spider webs, and when it is time for small hand-paint tattoos, he is always included. His picture – a heart, a small apple, or a sailboat – is always painted by his eight-year-old sister. The therapeutic clown becomes adept at balancing the needs of healthy siblings with the needs of the child who is the patient. It is not unusual for the clown to look up and see that all members of the family, including teenage siblings and parents, have been drawn into the space of the play. Sometimes, the play has all the hallmarks of an impromptu party. The therapeutic clown may visit the home on several occasions after the death of a child to maintain her relationship with siblings who have come to know her well. Flora also has a website (www.floraclown.ca) so that siblings can stay in touch if they wish.

Mastery and Empowerment

Added to the clown's vulnerability and openness is a certain inability to cope with the details of everyday life resulting in confusion and ineptness as well as a good measure of humor. Clown historian John Townsen (1976) suggests that "the clown's ability to evoke feelings of superiority in the spectator plays a hidden role in all clowning" (p. 206). The therapeutic clown works to empower children, offering choices and encouraging a sense of mastery at a time when there may be many limitations in their lives. It could be said that the therapeutic clown exists in a state of potential, waiting to be completed by the child, so that each child has the clown most suited to his or her needs. A small child can give advice about hand-washing and managing paper-towels, or tell Flora that a bubble she can't find has simply popped. A child can initiate Flora into the world of dinosaurs or transformers. Children delight in putting Flora to sleep with the tinkling notes of her magical music box, waiting only for the moment when they can shout and see her wake up with a start – a giggle-inducing piece of play which is repeated many times. The therapeutic clown is at the service of the child and is a most amenable playmate as the play unfolds in satisfying ways. However, the therapeutic clown must be skilled in keeping the play and the players safe. She must be aware of lines and other hospital equipment, as well as of the needs of other staff as they care for the child. After one game of hide-and-seek, involving my clown Posy and a four-year-old child hiding in the bed curtains while his father loudly stomped around looking for them, the child burst out into the room yelling, "Power Rangers, attack." Then turning to me, he added, "Bring my IV, Posy."



Children will often take care of their clown friend, painting a small picture on her hand, retrieving forgotten toys, or helping Flora fit things back into the toy box. One child liked to do up the buttons on my coat as I left her home after a visit. An over-excitable Bunny puppet was the occasion for a child to express her need to offer care as well as receive it. In a relationship that developed over many months, this ten-year-old girl taught Bunny how to breathe to calm herself, and rocked Bunny to sleep at the end of each visit. Bunny sometimes helped to distract her during painful dressing changes. In fact, Bunny became such an important part of the play that Flora the clown all but vanished; I was simply there to bring Bunny to life.

Play and Humor

The therapeutic clown is in her person a most vivid invitation to play. After she asks permission and steps over the threshold into a hospital room, a living room, or a bedroom, anything can happen.

Play is both a right of the child – Article 31 of the United Nations Convention on the Rights of the Child - and a normal activity of childhood. Play in health care environments is “an essential element in reducing the degree of threat perceived by children in the new and unfamiliar surroundings” (Gaynard, 1998, p. 248). Sourkes (1995) comments that play enables the seriously ill child to “reenter” childhood (p. 5).

The therapeutic clown is not a play therapist but properly engages in therapeutic play. Christina Brown (2001) defines therapeutic play as “play that facilitates expression, coping, and mastery. It addresses the child’s need to express feelings, solve problems, and work through or resolve conflicts or distress” (p. 250). Brown continues: “Generally speaking, play that is predominantly child directed and open ended and that invites the child’s verbal or non-verbal expression of thoughts and emotions may be considered therapeutic” (p. 258).

The play space has been called the magic circle (Huizinga, 1955). This space can be created inside the larger space of the hospital or home. It may be an intimate space, small enough for two or it may be big enough to encompass every member of a family and whole worlds of the imagination. Because play is a framed event with a beginning and an ending (Sutton-Smith, 1984), each playtime can have a satisfying shape – whether it lasts for an hour or just for a few moments. Information acquisition and learning have been described as a breathing in (Jaffke, 1996). For the child, and indeed for the family, illness and hospitalization are a huge in-breath. Free play offers opportunities for breathing out. Perhaps most importantly, play space is safe space. In the play space, the child can perhaps find what Sourkes (1995) describes as “a ‘safe place’ within the storm” (p.81). The players make the rules. Together, as O. Fred Donaldson (1993) says, they become, in this meeting place, “a new ‘we’” (p.32).

The play space is a generous one, open to whatever comes its way. A bubble play with a child on the hematology/oncology unit prompted a father to say: “You know what the photographers say? Life’s a bubble. Picture it before it explodes.” Sometimes the play offers a parent the opportunity to express the inexpressible. A little wind-up bear that had to be tapped on the head to get it moving occasioned this comment from the mother of a nine-year-old girl. “If I tapped you on the head, would you go on?”

With play comes much needed humor and lightness. The child and family’s situation is extraordinary, but there is time and space for some appropriate levity. Within the safe play space and in the context of a supportive relationship with a therapeutic clown, children can express their own humor. A three-year-old child in the ICU, on a ventilator, with a tracheotomy, took the end of Flora’s slinky and with a glint in his eye turned it into a steering wheel. When Flora laughed, a passing health care worker said: “He’s making the clown laugh!” For parents, seeing a smile on the face of their child can be beyond value, and never forgotten. Many years after I had worked with a child who died of cancer when she was four, I met her mother at a hospital event. She introduced me to her colleague as the person who was responsible for her daughter’s last smile.



The Play Conversation

Play between a child and a therapeutic clown often follows predictable and comforting paths and takes on all the familiarity of a revisited conversation. Children look for familiar toys in a clown's kit, and request the same game over and over. "You know what I like painted on my face," said one small boy. As the child becomes less able to play, the therapeutic clown takes on the role of facilitator helping the play to continue as long as the child wishes. A six-year-old girl, not long before her death, communicated to Flora every detail of the hand-paint design of hearts and flowers she wanted, even though she could only indicate "yes" or "no" with her eyes. As Hilden and Tobin (2003) point out: "With their natural tendency to live in the present and their ability to cherish play and other pleasant experiences, dying children often astound the adults around them" (p. 8).

Conclusion

The therapeutic clown travels with a small kit of bubbles, puppets, toys and games, but it is equally important that she have a repertoire of songs, stories, and skills. Working in the context of family-centered care, she moves from singing to babies, to toddler play; from shared imaginative storytelling, to hanging out with teens. Often the entire family gathers around when a clown visits. The therapeutic clown working in the area of pediatric palliative care must also understand that the quality of her presence is as important as the diversions she offers. In some situations, it is all she can offer.

The therapeutic clown, especially one who can move between hospital and home, can become a welcome and trusted presence for children and their families who are receiving palliative care. The clown, by her very nature, "enhances life" (Hoyle, 1989). She honors the right of each child to play as long as he or she is able. She offers opportunities for creative self-expression, empowering play and gentle humor that include the child, siblings, and other family members. During these times of respite from the concerns of illness, videos and photographs are taken, and memories are created. For the therapeutic clown it is a privilege to witness the journey of children and families as they face the realities of life-threatening illness and impending death. And a privilege to contribute to a child's "good day."

"Posy the clown dropped by and she and James had a ball together.
So it was a good day."

Syd Birrell. *Ya Can't Let Cancer Ruin Your Day: The James Emails*.

I wish to express my gratitude to my colleagues, the members of the Palliative and Bereavement Care Service at SickKids in Toronto.

References

- Antle, Beverley J. et al. "Paediatric palliative care: What do parents want?" *Rehab and Community Care Medicine*. Fall, 2005, pp. 24-26.
- Birrell, Syd. *Ya Can't Let Cancer Ruin Your Day: The James Emails*. Green Train Books, 2005.
- Brown, Christina D. "Therapeutic Play and Creative Arts: Helping Children Cope with Illness, Death, and Grief." In Ann Armstrong-Dailey and Sarah Zarbock (Eds.), *Hospice Care for Children*, pp. 250-283. New York: Oxford University Press, 2001.
- Cline, Paul. *Fools, Clowns and Jesters*. La Jolla, CA: Green Tiger Press, 1983.
- Donaldson, O. Fred. *Playing By Heart*. Deerfield Beach, Florida: Health Communications, 1993.
- Gaynard, Laura. "Play as Ritual in Health Care Settings." In Doris P. Fromberg and Doris Bergen (Eds.), *Play from Birth to Twelve and Beyond*, pp. 248-256. New York: Garland, 1998.



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- Hilden, Joanne M. and Daniel R. Tobin. *Shelter from the Storm: Caring for a Child with a Life-Threatening Condition*. Cambridge MA: Perseus, 2003.
- Hoyle G. *The Fool Show [program notes]*. Bayview Playhouse, Toronto, 1989.
- Huizinga, Johan. *Homo Ludens*. Boston: The Beacon Press, 1955.
- Jaffke, Freya. *Work and Play in Early Childhood*. Edinburgh: Floris Books, 1996.
- Liben, Stephen, Danai Papadatou and Joanne Wolfe. "Paediatric palliative care: challenges and emerging ideas." *The Lancet*. Vol. 371 (March 8, 2008), pp. 852-864.
- Sourkes, Barbara. *Armfuls of Time: The Psychological Experience of the Child with a Life-Threatening Illness*. Pittsburgh: University of Pittsburgh Press, 1995.
- Sutton-Smith, Brian and Diana Kelly-Byrne. "The Idealization of Play." In Peter K. Smith (Ed.), *Play in Animals and Humans*, pp. 305-321. Oxford: Basil Blackwood, 1984.
- Towsen, John. *Clowns*. New York: Hawthorn Books, 1976.

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USE OF POSITIVE IMAGES AS A SPIRITUAL INTERVENTION

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This article is based on my experience and observation of the impact of positive images and meditative music on patients in a pediatric hospice and palliative care setting. As a chaplain for Stepping Stones, one of the ministries of the Providence Hospice of Seattle, I serve the needs of pediatric patients, their siblings, and adult family members. The purpose of this paper is to share an array of possibilities that technology can provide to create reflective and relaxing moments in the lives of patients and their families. The growth of technology and its penetration into many aspects of daily life provides a flexible and creative tool to bring different types of emotional and spiritual support to patients and their families in a non-verbal yet effective form.

David Hodge offers a definition of spirituality as a relationship with God or whatever is to be held Ultimate that fosters a sense of meaning, purpose and mission in life. A sense of having a spiritual relationship with Self promotes a more meaningful sense of personal well being. The goal of spiritual care is to assist and witness patients' struggle in maintaining personal realization of one's own spirituality and understanding of one's placement toward the desired symbol of well-being. By leaning on personal, faith, cultural, and community resources, the chaplain ministers to the existential, spiritual, and emotional needs of patients and their care providers. This ministerial task may take different forms including:

- supportive listening;
- performing rituals or providing information on local community support if patient and family specifically desire a religious ritual to be performed that is different from the chaplain's own tradition;
- providing spiritual readings;
- creating sacred space for patient to review life story in order to discover personal strength and constructive spiritual tools used in previous life struggles;
- leading and teaching meditation to create daily relaxing and reflective environment as a way to self-control;
- use of game and art therapy;
- and if requested to provide prayers.

However, due to the different developmental needs of children, a pediatric chaplain strives to find appropriate ways to encourage and support a relationship with the sacred in the ordinary life of pediatric patients and their families. Children and adult spiritual needs may vary from need for assistance to cope with disappointments, depression, feelings of guilt, anger, and resentment toward shattered images of the future; struggling to make extreme hopes to come true and feelings of marginalization and isolation due to the lack of ability to participate in extracurricular activities. Use of positive images and meditative music helps to create a reflective experience that fosters quality of life for pediatric patients and their families, and could be used as a developmentally appropriate and intergenerational activity.

How does it work? To create a presentation, I first search online in different search engines for beautiful images representing the universe, stars, planet Earth, and the natural world. Searching for keywords such as compassion, healing, and hope provides related pictures. I then compile these images into a PowerPoint slide show, which involves resizing the images to cover each slide and ordering them into a "visual narrative," along with words of wisdom from different faith traditions and poetry. If an image is too small to cover the slide, then a black background helps to create a more vivid presentation on the wall.



My.NHPCO: NHPCO's Social Networking Site for Members Will Benefit ChiPPS

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Facebook, Twitter, MySpace, YouTube, Flickr, LinkedIn, Blogspot—Internet sites that were unfamiliar to most people only a couple of years ago are now part of daily life for many Americans. Tweeting, texting, posting, linking, surfing have new meaning in our contemporary vocabulary.

What many refer to as social networking tools were created to facilitate communication between two individuals, however, the professional world has been quick to adopt these communications tools and see how they might benefit life in the work place.



Launched earlier in 2009, [My.NHPCO](#) is a new, online networking community created expressly for the use of NHPCO members across the country. Similar to other popular networking sites, My.NHPCO gives members the power to share their experiences and knowledge with their peers. It allows users to participate in end-of-life care discussions through blogging, document sharing, resource ranking, eGroups—which are improved listserves—and much, much more!

My.NHPCO can be a valuable tool to those active in ChiPPS. While membership in NHPCO is required to access the social networking environment, users will most likely find many professional benefits. First, let's look a bit more at this new tool.

While the full impact of social networking as a professional tool in the work place is unknown, the power of this medium cannot be questioned. More and more organizations are integrating these tools as part of their communications strategy and are only now beginning to assess the effectiveness of these changes. Among the hospice and palliative care community, there has been any number of early adopters. For example, San Diego Hospice and its Palliative Care Center has been active on Twitter for some time, Alive Hospice in Nashville launched their successful online blog last year, and the blog Pallimed.org has established itself as a valuable source of news and information. Now, NHPCO has launched its own social networking community online, My.NHPCO. These all reflect significant changes in the way professionals communicate.

Christy Torkildson, co-editor of the ChiPPS newsletter offers some thoughts about My.NHPCO, "It is a different type of tool than the old listserve ChiPPS used previously. However, My.NHPCO is not eliminating the listserves but updating them to be more robust tool for those involved with ChiPPS. The new system will archive past discussions that will be searchable allowing us to benefit from previous discussions that were lost with the old listserve. We can also post documents and videos and share attachments with others which was not an option with the old listserve."



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care Organization



Due to increasingly vigilant SPAM filters and virus protection being put into place by organizations, a great number of NHPCO members could not participate in the old listserves from their workplaces. And the old listserves could open up home emails systems to potential viruses. My.NHPCO expands the reach of our members and facilitates virtual communication safely and responsibly.

The major difference is that ChiPPS participants who wish to use My.NHPCO must also be NHPCO members – but more on that later in this article. What are some of the specific benefits?

MY.NHPCO Users are able to:

- Create your own personal profile that is pre-filled with information from NHPCO's membership database. Your profile is secure and may be expanded by completing additional fields of information;
- Define who may view your profile and what information site visitors can see;
- Participate in pre-established eGroups, like the ChiPPS eGroup, or many other eGroups based on topics of interest or professional discipline;
- Search past eGroup discussions for specific topics of interest—a feature unavailable with the previous listserves;
- Share documents via online libraries and browse other documents posted by members—our previous system did not allow for the safe and secure sharing of documents;
- Search the NHPCO directory to find colleagues and friends—and categorize contacts into personally defined groups such as co-workers and fellow committee members;
- Explore the contact lists of fellow contacts to identify mutual friends; and
- Create your own blog, follow other users' blogs—and much more

Responses from members have been as varied as the membership itself. For example, Rhonda Kurvink of Oklahoma's Hospice of McAlester, quickly felt at ease telling NHPCO, "I don't like change, especially when I don't have time to figure it out or make the transition! This said, I took time on Friday evening, after work to review and set up my profile at My.NHPCO and surprise it really wasn't so difficult or time consuming! Like the little engine that could, 'I THINK I CAN, I THINK I CAN' became, WOW, I DID IT!" Flexibility is what makes My.NHPCO such a useful tool. Users may take advantage of as many or as few of the features that they choose. Users need not fill out all the fields on a profile and can be selective about what other users can see on their profile. The system is secure and will actually prevent some of the threats that accompany traditional email communication.

Based on NHPCO's beta-group testing and the initial member feedback, the ease of use will come with only a little bit of patience and practice.

Oklahoma's Greg Wood shared some helpful thoughts with other members, "As with all things, we will have adjustments to make, new methods to learn and probably kinks to work out, but this new method of communicating with each other will enhance our abilities to share documents, questions, blog on professional topics, as well as learn more about each other as we begin to slowly add information about ourselves and our organizations."



Those active in ChiPPS who are current NHPCO members, already have access to My.NHPCO. Steps to enter the system, if you never have done so, are included below. If you are involved in ChiPPS and are not a member of NHPCO, there is a category of membership that will bring this new tool – and many other resources to you – this is membership in NHPCO's National Council of Hospice and Palliative Professionals (NCHPP). NCHPP gives you full access to My.NHPCO and other benefits available from NHPCO, such as weekly e-NewsBriefs, conference and Marketplace discounts, access to members' only section of the NHPCO Web site, and more.

To join NCHPP, you can contact the NHPCO Member Services Center at 1-800-646-6460 or go to www.nhpc.org/nchpp to learn more and download an application. Remember, if you work for a current provider member of NHPCO, you're entitled to free e-NCHPP membership.

"I hope everyone working with ChiPPS will take time to get to know My.NHPCO," Torkildson advised. "Yes, there will be a learning curve, but the ability for us to reach out and share and learn will be greatly enhanced."

How to Access My.NHPCO

To enter My.NHPCO, go to <http://my.nhpc.org/> or look for the My.NHPCO link on the NHPCO homepage (www.nhpc.org). Then, getting started on My.NHPCO takes four simple steps:

1. Login with your NHPCO login account

All current NCHPP and e-NCHPP members have their own user ID and password. All staff and volunteers of provider members are entitled to complimentary e-NCHPP membership. If you don't know your password/ID, contact NHPCO Member Services at 1-800-646-6460.

2. Click on "My Network" to update your NHPCO Professional Profile

Your profile is populated with the basic information from your current member record. You don't have to add any more information if you choose not to. Adding a photograph is also optional. However, the additional fields will let you tell other members a bit more about yourself. Share only what you're comfortable including. You can change your profile at any time.

3. Search for your colleagues and add them to your contact list

Build your own network of contacts out of all the other members currently using My.NHPCO. Group your contacts by interest, topic, and region – whatever seems to make the most sense for you. This is also optional and something you can do over time if you choose.

4. Join eGroups based on interest

Each hospice/palliative care discipline or job function has a eGroup already established, as does the ChiPPS section. Once you've gone into your profile, you can join any number of eGroups by clicking on the eGroups tab, that's where you'll find the ChiPPS eGroup listed, under the Topics section.

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Items of Interest:

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

- 1. Subjects and Contributors for Future Issues.** Previous issues of this newsletter have addressed a wide range of subjects, including bereavement, sibling bereavement, self care, ill and dying teens, perinatal loss, neonatal loss, spirituality, unsung heroes in the circle of care, pain and symptom management for children with life-threatening illnesses and their families, families experiencing transitions associated with pediatric palliative care, and now complementary therapies.

For future issues, we are thinking about addressing subjects such as the status of pediatric palliative care in the United States (e.g., financing and sustainability; why do some programs succeed and others fail), memory making and legacy building, global perspectives on pediatric palliative care, and developmental considerations. If you know of good topics and/or contributors (including yourself) for any of these and/or other future issues of this newsletter, please do not be shy! Step right up and contact any of the following: Christy Torkildson at torkc@sbcglobal.net; Maureen Horgan at Maureen.Horgan@providence.org; or Chuck Corr at ccorr32@tampabay.rr.com. We will be happy to work with you!

- 2. Previous Issues Available Online.** Please note that archived issues of the ChiPPS newsletter may be found online at www.nhpco.org/pediatrics. Please take advantage of the previous issues that offer a wealth of valuable information!
- 3. Reader's Corner.** This is an occasional feature in our newsletter that provides brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric palliative care, but that may not be known to all readers of this newsletter. Contributions to the Reader's Corner include an abstract of the publication, a description of the audience for this information, comments on what is special about the publication, and suggestions as to where and how this information can be applied. We welcome suggestions for publications to include in our Reader's Corner and/or summaries and comments on helpful articles (check issue #13 available at the newsletter archive if you'd like an example of the format to follow). Please send all such suggestions to Christy Torkildson at torkc@sbcglobal.net.
- 4. December 2009 Conference.** The National Hospice and Palliative Care Organization will host the **6th National Conference on Volunteerism and Family Caregiving**; December 4-6, 2009 at the Walt Disney World Swan in Lake Buena Vista, FL. Interested participants may register onsite at the conference. More information is available at www.nhpco.org/conferences.
- 5. Pediatric Palliative Care at Clinical Team Conference 2010.** ChiPPS is proud to offer a pediatric intensive track that as part of NHPCO's 11th National Clinical Team Conference to be held in Nashville, TN, September 13 - 15, 2010.
- 6. CTC Call for Proposals Coming Soon.** In the next few weeks the call for concurrent session proposals that will be part of the pediatric intensive track at the Clinical Team Conference in Nashville will open. Please check the NHPCO Web site for information on submitting a proposal--this is all done online, so keep a lookout for the link under "Breaking News" on the NHPCO Home page.



- 7. AAHPM Meeting in 2010.** The American Academy of Hospice and Palliative Medicine, in collaboration with the Hospice and Palliative Nurses Association, will host its Annual Assembly on February 16-19, 2011; Vancouver, Canada. Further information can be obtained from the Academy's web site, www.aahpm.org or by calling 847-375-4712.
- 8. Calendar of Events.** As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, www.nhpco.org/pediatrics. *ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.* Please e-mail Christy Torkildson at torkc@sbcglobal.net to have your pediatric palliative care educational offering listed.
- 9. Online Courses in Collaboration with the National Center for Death Education (NCDE).** NHPCO is proud to collaborate with the NCDE at Mt. Ida College in Newton, MA to provide ongoing educational programs for hospice and palliative care professionals and volunteers. There will soon be a series of courses specific to Pediatric Palliative Care! These online courses enable you to acquire and maintain a current knowledge base, as well as develop creative and useful skills for providing care associated with end of life, bereavement and loss. For more information about NCDE, visit mountida.edu/ncde or contact NCDE at 617-928-4649.
- 10. "Standards of Practice for Pediatric Palliative Care and Hospice" available from NHPCO.** NHPCO has released national standards for pediatric palliative care and hospice that were developed by NHPCO and ChiPPS to address the needs of young people and families facing serious and life-limiting sickness. Learn more about the "[Standards of Practice for Pediatric Palliative Care and Hospice](#)" online. NHPCO members may download the [pediatric standards in PDF](#), at no charge. A printed copy of the pediatric standards is available to purchase from [NHPCO's Marketplace](#) online or by calling 1-800-646-6460.
- 11. New NHPCO Pediatric Facts and Figures (2009).** In addition to releasing "Standards of Practice for Pediatric Palliative Care and Hospice," NHPCO has a new report, "[NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America](#)" (PDF), available to download for free. The report was written by Sarah Friebert MD, NHPCO's medical consultant, and provides an overview of the landscape of pediatric palliative and hospice care for providers, policy makers, funders and the media.
- 12. Support Partnering for Children/Wear a Bracelet.** Partnering for Children (www.partneringforchildren.org) is a national awareness campaign that was launched November 2007 at NHPCO's Clinical Team Conference. The goal of Partnering for Children is to help get the word out about compassionate, family-centered healthcare for children with life-threatening conditions. The ChiPPS work group and the resources ChiPPS makes available is an important part of this campaign.

In the memory of the many children whose wisdom and courage inspire us, inspirational bracelets developed by [Children's Hospice and Palliative Care Coalition](#) are now available through Partnering for Children. These inspirational bracelets which bear poignant messages from children can be ordered directly online at partneringforchildren.org or by calling 800-646-6460. One hundred percent of the net proceeds of these bracelets go directly to improving care and quality of life for children with life-threatening conditions. For more information on the Partnering for Children campaign, including how to join as a campaign partner, please visit www.partneringforchildren.org.



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



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

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

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