



E-NEWS

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Issue Topic: Unsung Heroes in the Circle of Care

Welcome to the twelfth issue of the ChiPPS electronic newsletter. This e-newsletter links to a PDF collection of articles contributed by family members and professional colleagues. The newsletter is produced by ChiPPS (the Children's Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO's Communications Work Group, co-chaired by Christy Torkildson and Mary Kay Tyler.

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

As we prepared to send out this issue we struggled with those voices in our circle of caring who were not being represented. One of those is the voice of the funeral director, the person who comes and finally takes away someone's precious child. One of those individuals was Paul, owner and director of a family owned mortuary for more than 40 years.

Paul knew what it was like to lose a child; he and his wife had lost a son, many years ago. Since then Paul has seen many losses, including another child and his wife. When I [Christy] approached Paul about writing about his experience with pediatric palliative and hospice care he lit up and just beamed, but then quickly sobered as he shared he had just been told that morning he had lung cancer and it "doesn't look too good." This was three months ago. Yesterday Paul died.

Paul was a giant of a man in physical size and especially in the size of his heart. He would often come to pick up a child himself, making a point to always connect with the parents however they could bear. He would ensure that every child had a wonderful celebration of life for their family and friends, often paying for services out of his own pocket. He gathered friends together from all aspects of his industry, this industry that most individuals can barely talk about, to make sure that all aspects for funeral planning and services would be made available to any family in need. After the sudden death of one child, whose family lived in South America and whose North American family insisted that an open casket was critical for her family to say good-bye, Paul arranged for a specialist to come from out of state to make that happen. I won't go into details, but there was an open casket viewing and everyone was able to say good-bye to the child they had known.



I believe that in the work we all do we all have one or more Paul. These are individuals who cross our paths and then walk beside us doing whatever they can do to lighten the load, often going above and beyond any expectation. This is very special work we do in all its various aspects—inpatient, outpatient, home-based, consulting, wherever and however we reach and touch children and families facing life-threatening conditions. There are many others who deserve mention, those who help us expand our circle of caring. However, in practice we cannot include all of them in one newsletter, but we ask that you think of who those folks are in your own circle and let them know how much they are appreciated. Perhaps sharing this e-newsletter with them might be one small way to let them know that they too belonged in this issue.

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Issue #12: Unsung Heroes in the Circle of Care

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

Notes from Pediatric Palliative Care (a volunteer) ***p. 4***

Mary Case, MD

Mary, an adult hospice volunteer for over a decade, first describes how different her pediatric experience has been. Then she leaves us with four things she has learned from the families she has served.

It Doesn't Matter What We Do (a volunteer) ***p. 7***

Greg Smallidge

Greg tells the story of a teenaged sibling who finds normalcy through his interaction with a hospice volunteer.

My Ongoing Journey as a Child Life Specialist ***p. 9***

Patricia Frasca, MS, CCLS

Patricia describes how a child life specialist, as a member of a Palliative Care team, can support children and families. She does this through the story of a resilient child, Tameka.

Hydrotherapy for Children in a Pediatric Palliative Care Setting ***p. 11***

Sheila Pyatt, RN

Sheila describes the many benefits of using hydrotherapy with serious or terminally ill children. In addition, she shares her belief that this work reflects the truly holistic nature of nursing.

Gentle Notes: Music's Role in Pediatric Palliative Care and Hospice ***p. 15***

Tami Briggs

Tami illustrates how music can provide comfort, create a peaceful environment, and add richness to the sacred experience of dying.

Art for Life: Choosing to Make a Creative Difference! ***p. 17***

Anthony Knutson

Anthony outlines the purpose of the Art for Life foundation, which is to help children heal through art. Not only are the children able to be healed through their art work, they are also able to leave a legacy. Web site: www.artforlife.org/.

Through My Lens: Moment by Moment ***p. 21***

Karen Henrich

Through her photography, Karen captures lasting memories of dying children, memories that will be cherished forever by their families and friends. Web site: www.momentbymoment.org/.



Witnessing Words: Writing and Palliative Care

p.22

Nancy Iverson, MD

Nancy illustrates how words, specifically poetry, can be used to help patients and families express their innermost feelings and emotions. Professionals can help patients create a journal of poetry to be left as a legacy.

A Rewarding Experience: A Teenage Volunteer's Reflection

p. 32

Maeve Gallagher

Maeve briefly describes what the experience of working as a teen volunteer in pediatric palliative care has meant to her.

Items of Interest

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

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



NOTES FROM PEDIATRIC PALLIATIVE CARE

Mary Case, MD
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The two of us, the little girl and I, we sit on the living room floor around the baby. We ask him gibberish questions, and repeat his name in a singsong voice. Together, we read a story aloud. We tell him what we've been doing while he slept. We show him what we're learning – whistling, dancing, and how to click our tongues. (They're not-quite-clicking yet.) We laugh together, just like every family.

I became a pediatric volunteer after serving as a clinical associate for a Robert Wood Johnson-funded Pediatric Palliative Care Grant in Washington State. The program was conceived and executed through the talents of the same extraordinary people who work on it today. I'd volunteered in an adult setting for over a decade, but found that volunteering for families whose children have life-limiting illnesses is a uniquely different experience and learning opportunity.

First, the role families are programmed to perform is "raise a perfect child." Each of us plans, prays, or wishes for our definition of a perfect child. One thing that all of our definitions have in common is a child who lives a long, healthy life. All of us have memory – not just the regular kind about the past, but one about what the future will be, too. When a baby is first conceived inside our heads, she is bestowed with a name, a personality, a set of school activities and accomplishments, a commencement from family of origin, and perhaps even a glimmer of grandchildren. We expect to parent twenty years, live many decades, and then end our lives in a reversal of the parent-child role. So when your child is born with or develops a life-limiting illness, it's nearly impossible to wrap your brain around the very fact of it.

Second, in children, the trajectories of many life-limiting illnesses are very different than in adults. Children may have periods of relatively stable well-being in-between periods of fragile or deteriorating health, when an adult with the same diagnosis would have a more predictable course. A week of apparent active dying may be followed by a month of high quality of life events, and parents may feel that they are doing things with their child for the first time, rather than the last. All this presents unique opportunities to the kinds of support a hospice volunteer gives.

Third, and also in contrast to adult hospice scenarios, families in this setting have rarely been the beneficiaries of volunteer help. Of course, they have been volunteers before, with their own extended family, maybe, or at church or school. Such volunteering can be social, celebratory, or charitable, but it is always defined and discretionary. It is one kind of acceptance to have a nurse, a social worker, or a spiritual adviser in the home. They have direct, easily understood roles to play. It is quite another to invite a non-family member with a less-clearly-defined role into the home once a week.

"For what?" a parent might ask. To be on death watch? To entertain? Do I leave the house while the volunteer is here? Do I leave the room? *What do I do with a volunteer?*

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At the beginning of every volunteer shift, I pause before knocking. I always take in what stands out on this side of the door. It is an ear-piercing clue to what is on the other side. Sometimes there are one or more newspapers. Sometimes there are plants, thriving or waiting stoically for something more than the sun. Sometimes there are ornaments, marking the current season or left over from the last holiday. Sometimes there is a blank landscape, as if family life exists only on the other side. Before knocking, I attend to stopping any chatter inside my mind, and emptying it. Emptying everything in preparation for the milieu present today, on the other side of the door.

As the door closes behind me, I smile, wash my hands, and greet each person there. Then I listen. To whatever is going on at the moment. To whoever asks for my attention. My orbit is always around the parent.

What happens when a volunteer comes each week? First, the parent has the ability to carve out a personal agenda. She may identify tasks to complete. Going to the grocery store, for example, or shopping for a sibling's birthday. A friend's anniversary. Or she may have enthusiasm for tasks like cleaning a room or making a memory scrapbook. Later, she may schedule appointments for a sibling, which may include a side trip on the way home. For her, this regular oasis of uninterrupted, discretionary time is energizing.

Additionally, it gives her an opportunity for self-reflection. A mother may descend from upstairs at the end of a shift, saying she became caught up in watching a spider weave a web in the windowsill, and lost all track of time. Or she may take time getting ready for the respite that the volunteer brings, and look into the mirror for more than a casual glance. Then, in response to a compliment, she will relate a memory about getting ready for her first date with her husband. Losing track of time and remembering a happy personal experience are invaluable, normal events that a hospice volunteer can help to reinstate in a household.

The siblings experience a new person who treats them like a wonderful family. A person who knows the past, apparently sees the future, and still comes back each week with a light heart. A person who plays with them, models for them with the patient, and cheers their parent. A person who laughs, and teaches little things, like how to click your tongue.

The patient receives loving care from the volunteer each visit. In some families, this means a care routine focused solely on the patient – feeding him, playing with toys interactively, or presiding over his nap. In others, it means variety of events designed entertain the siblings while the parent enjoys one-on-one time with the patient. At the end of every visit, the volunteer gives integral feedback to the parent. “The patient was awake while we read stories, and then had a restful hour nap.” “The patient really enjoyed having her brother on the couch beside her while we watched the video.” “Wow! The sibling learned to tie his shoes since last week!” All of this is patient-centered, volunteer palliative care.

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Here are four things I've learned from volunteering with pediatric hospice families:

Place yourself exactly where the patient and family is, each time you see them. The most important thing is what is going on for the family that day. Immerse yourself in that. It is the only thing that matters.

Expect things to change. In three months, a child who loved to pick out one video from a vast collection and then giggle through it until he fell asleep may get the same measure of joy from



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simply picking out the video, and holding it in his hands. One week, siblings might jump out of their skin to take a trip to the park, but during the next they'll be happy coloring for an hour, just to be in the same room as their parent.

Depend on the team. There are some things we hear because we are there at the time, like a gut-wrenching phone conversation with a grandparent. There are some things we see first, like the holistic light and heat treatment recommended and administered by a sister-in-law. And there are some things we sense first, like the isolation of the sibling who cannot do after school activities because of the parent's commitment to caring for the patient that time of day. It is uniformly appropriate to pass these experiences, as well as your ideas or recommendations, onto the team so that the next step can be determined. Pass on, immediately, changes in the patient's capability and comfort level. Field any question from a family member by redirecting it to the team.

Inhale – literally. Take a breath after closing the door the door at the end of the shift. Be full of gratitude, both for what you have done and for what you have received because of this family. Be full of gratitude for the people and things in your own life which allow you the opportunity to volunteer. Do something to replenish your reserve. And listen to some good music on the way home!

Volunteers are sometimes referred to as just part of a whole – the eyes or ears or heart of hospice, or even a one-person remote control. But we are different than that.

We are the only members of the team present each week for hours at a time, and the only ones whose role is independent of our professional expertise. We are the ones who come regularly because of the patient, for the family – just to build a blanket tent in the living room, fix lunch, or rock a child to sleep. We are a steady presence from the other side of the front door, a counterweight to each family's life. And as we respond consistently to changing needs, each week, we also ground a family's emotions and thoughts for what is to come.

In fact, we are ballast, giving stability and balance as the family moves along to a future they could never have imagined. A future with this child they love.

She looks up, shouts my name, and opens her arms for a hug. It is after all, the memorial service for her baby brother. The girl is perched on the lap of one of the mainstays of half of her life – her hospice chaplain – and holding a plateful of exotic potluck food. Fully recognizing me now, she changes in a flash, throws her head back, laughs, and says, "Look what I can do!" She clicks her tongue, expertly now. I click back. And then, just like every family, we laugh together.

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IT DOESN'T MATTER WHAT WE DO

Greg Smallidge
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It's always exciting when I meet a new family. Driving to their home for the first time, I'm usually a little nervous about wanting our visit to go well. I'll have already learned from the hospice staff lots of information about this family (everyone's name, the kids' ages, the medical condition of the patient, etc.), but it's only after walking through their front door – seeing their faces, talking with them, taking in their energy – that I really start to know them.

And I'm aware that they are checking *me* out, politely but intently looking me over – to see if they trust me, like me, and feel comfortable having me around their children. I'm a parent, too, so I understand this and I'm not insulted by it. Sometimes they've said no. Maybe they decided they don't really want volunteer help at all, or maybe they decided they just don't want help from *me* (a stranger, and a 46-year-old male). Because they don't have to accept my offer to work with them, it feels like an honor when they do. They just chose me to be a part of their family.

That's how it starts. Now I'm in. But we probably don't know exactly what it is I'm going to *do* yet. We know that I'll be there every week for four hours, and we've talked about the kinds of things I could do, and have done, for other families – but this family will be different. Their needs are different and their relationship with me will be different. One part of this volunteering I love, and that feels so wide open, is that the family and I create this relationship as we go. We walk a path that's new for all of us, not knowing how long we'll walk together or what it's going to look like (and feel like) along the way. It means there are going to be surprises...

My current assignment is with a large, collected family. Some of the kids are adopted, some have medical needs, and the youngest has a life-threatening condition. Max is an engaging, bright-eyed boy with a disease that (among other things) makes his skin incredibly unstable. He lives with open wounds, blistering and pain, and requires full time care from his family. I'd been told about his condition and warned that some of the realities were pretty gruesome. The parents are in their 60s, raising this second family, dealing with their own medical issues, and keeping it all together – with grace and tremendous heart.

I felt some pressure to be really great for this family – to be open and accepting and to stick around (the previous volunteer didn't come back after the first visit). I was braced for the worst, and wondering whether I would be as capable and helpful as I wanted to be.

It's funny how things work out. Little Max does have this crazy, unbelievable disease – but it was so easy and immediate to see, and be taken by his delightful spirit and energy. He's an amazing boy I'm lucky to know. He's also a boy I have had little contact with in the six months I've been with his family. So what have I been doing?

Well what Max's mom figured out early on was that David (fourteen and funny and sweet) may be the person in their family most in need of attention and having someone to hang out with. Max requires an enormous amount of care but was getting all that he needed really. David needed a friend to go on adventures with – somebody who wasn't busy with his brother.



David's home is right next to a large forest – with hills and streams and lots to explore. We spend hours outside in these woods. This was something he wasn't allowed to do unless he had an adult available. All through the winter and now here in spring, we've discovered mysterious animal tracks and droppings, trails and swamps, lots of fallen trees, neighbor dogs – and also that we like to be together. It doesn't really matter what we do.

I fill out paperwork at the end of the month to document my volunteer time. When I get to this section ...

Document each contact by date in detail including issues, concerns, significant changes observed, interventions, and discussions with team members and coordinator.

... I feel like I ought to be writing something more serious than this:

David and I headed out into the woods again. We packed a lunch and a rope and worked on freeing a tree that had fallen in a storm.

The truth is we're just having fun. We have this unusual luxury of spending time together and playing without any real agenda – which is something I'm enjoying at least as much as David. It's certainly not what I expected I'd be doing – I was anticipating caring for a very sick young boy and I find myself playing video games, hiking in the woods, and eating hamburgers with a healthy teenager.

Just a couple things haven't been so fun. There was the time when the kids were fighting really rough and mean and I didn't know what to do. There have been boundary issues, and even legal issues to clarify. I didn't handle any of these on my own. I have my own support in the half a dozen people who make up the rest of the care team. We share information, ideas, and our perceptions of how things are going and what this family needs. We talk things through and get things right again.

Maybe because it's been so effortless and fun, I sometimes question whether my weekly visit with David really means very much – but only for a minute. I know the importance of having caring people around. I started volunteering here because my family got such helpful grief support from Providence Hospice after my father-in-law died. In particular, I saw the difference "strangers" could make with my son. What did they do? They were present with him, and they provided some normalcy during a hard time. And now I get to do that – get to be that kind of friend.

One day here, hopefully not soon, I know I'll be driving to a different house to meet a new family, wondering how it's going to go. But for now, my Fridays are filled with outdoor adventures, surprises, teenager silliness, and (usually) some kind of snack. It's a day filled with gratitude for being included in this family's life, and for the space we have in my family's life that allows me to do this work. And it's a day that I don't worry about what I'm going to do – I know I'm going to be with my new friend David, and it doesn't really matter what we do.

(Names and details have been changed to protect the identity of the family.)

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MY ONGOING JOURNEY AS A CHILD LIFE SPECIALIST

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My path to becoming a child life specialist (CLS) began in 1985 with my very first pet -- a one year old terrier mutt that I adopted from the San Francisco SPCA. Almost immediately, I began volunteering with their Pet Therapy program. I regularly brought my dog, Snickers, to pediatric inpatient units where I had the opportunity to interact with a few CLSs. I was immediately drawn to the profession and saw firsthand what it entailed. Eight years later and still volunteering, my employer offered an incredibly generous volunteer severance package. The door to becoming a CLS had opened. With the loving support of those who knew me well, I took the package, went to graduate school and have been practicing as a CLS in Northern California since 1995.

I have worked in a general hospital with a pediatric unit and PICU, an outpatient pediatric hematology/oncology clinic, an end-of-life/respite care facility, and a pediatric hospital. While the settings are different, the child life challenges remain constant – to provide psychosocial support to children and teens in various stages of physical health. The prevalent health care model operates from a deficit position, in essence, to fix what's broken and to offer services to those with certain risk factors (e.g., low family income, inadequate coping skills/family support). Child Life programs, by contrast, focus on strengths and interests as opposed to areas of weakness. It's been my experience that children and families benefit greatly when a resiliency approach is used, especially when a pediatric patient is receiving end-of-life care. My child life practice is rooted in the following definition of resiliency:

"...the capacity of individuals [and families] to cope successfully in the face of significant change, adversity or risk. This capacity changes over time and is enhanced by protective factors in the individual and the environment".¹

A CLS uses play to reduce stress and anxiety; developmentally appropriate and minimally threatening language to help pediatric patients make sense of their experiences; provides opportunities for distraction and self-expression; and promotes positive coping skills. Our venues are places children and teens are most familiar with – play/activity rooms and schoolrooms. The tools we use may be tangible and relatively simple, such as paper, markers, and play-doh, or intangible, such as facilitating a connection between patients in a non-threatening and familiar way. Much can be said about video game usage, but there is nothing more powerful than watching two introverted and miserable teenagers lose themselves together in an electronic game.

I am honored to have worked with patients who crossed the continuum of care – from palliative/curative treatment to palliative/hospice care. The therapeutic relationship developed over time provided familiarity, comfort, and trust for the patients and their families. While some health care professionals view CLSs as one-dimensional (i.e., "play lady"), I remain convinced that most families understand the comprehensive role of child life at its most basic level.

The following case example demonstrates one aspect of my experience as a CLS. My work with the following patient began when she was diagnosed with leukemia at age 7 and continued until she died shortly after her 12th birthday.



"Tameka" – an extremely resilient child

Treatment for leukemia was not easy for Tameka, yet she continued to thrive in ways one couldn't predict. She lived with her father and slightly older sister; her mother was in and out of her life. Family challenges continued until her death.

Tameka had a great sense of humor, an easy temperament, and a strong sense of purpose – all of which are considered to be resiliency protective factors. She defined herself as "a softy" and a peacemaker. She genuinely felt good when she helped another person, whether it was the janitor at school, another patient, or her classmates. Tameka had many stories to tell. "One time at school two girls were fighting. At first I thought 'Could you **please** take it somewhere else?'; then I said 'Could you try to work it out by using your words?'" She looked at me and smiled, knowing she had made a difference in their lives.

About six weeks before Tameka died, we began reading Because of Winn-Dixie – a book about a lonely 10-year-old girl, her father, a stray dog and an absent mother. I read a chapter a day to her, usually right before she fell asleep after receiving one of her meds. One day, Tameka began sharing her dreams with me, and she readily agreed to let me write them down. Sometimes we talked about the dreams, but usually, it seemed enough for her to share them with another person.

Here are the titles of some of Tameka's dreams:

1. The Butterfly Adventure
2. A Man on a Boat Going Down the River
3. The Bunny Who Was in Danger and Was Saved
4. The Bad Dream I Had and Hope I'll Never Have Again (separating from her father)
5. The Fish Who Almost Got Eaten by a Shark
6. The Day My Family Got Back Together Again

Tameka never talked about dying and sometimes spoke of the future. Her dreams were symbolically rich and seemed to provide her with a sense of comfort and well being. Regardless of your beliefs about dreams, I think it is difficult to miss the metaphorical interpretation of many of the words (e.g., butterfly, river) in her titles. Sometimes I wondered if a few of Tameka's dreams were really stories and her way of acknowledging that her physical life was coming to an end.

The experience working with Tameka was profound for me, and I continue to remain grateful for it. While not all child life experiences are as meaningful, I believe each interaction carries an opportunity for me to grow as a person – professionally, but also personally. My belief is that most of us who work with seriously ill children and their families are transformed by the experience. At a minimum, I think the "unlearned" lessons of life continue to present themselves at various times, with different levels of intensity. I am often reminded, for example, that while there is always more that can be done, sometimes what is done is truly all that is needed. I have never heard anyone use the word 'easy' to describe the work we do. For me, there are times when it can be fun, frustrating, sad, challenging, and rewarding, and sometimes, all in the same day.

As for my involvement with pet therapy, it has remained an important part of my life. For a brief time, I had the opportunity to bring my dog to work and to the home of a dying child. Suffice it to say that the therapeutic work done in the presence of animals cannot be easily explained with words. Some experiences must be witnessed to be truly understood. I am grateful that I deviated from my original career path and remain mindful that it all began with my first pet, Snickers.

Reference

Stewart, M., Reid, G., & Mangham, C. (1997), Fostering children's resiliency. *Journal of Pediatric Nursing*, 12(1), 22-31.



HYDROTHERAPY FOR CHILDREN IN A PEDIATRIC PALLIATIVE CARE SETTING

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I. What the supportive service is:

George Mark Children's House is the first freestanding children's respite and end of life facility in the country (www.georgemark.org). Skilled staff provides the best quality of care for families and children with serious or terminal illnesses. Among the many services provided, children with parental and physician permission can receive thirty minute aquatic sessions in a hydrotherapy pool heated to 96°F.

II. Why hydrotherapy is important at GMCH

When the hydrotherapy program at GMCH was in its early stages, night shift staff especially, started to notice changes in the children. They observed a child would sleep all night without waking, was more relaxed, or less stiff.

"I have never seen him so peaceful," states one mother, amazed at the decrease in hyperactivity of her severely brain-damaged child after about six sessions in the water.

Observations of staff and families supported my own previous experience in aquatics with adult clients. Whether in a recreational pool or a therapy pool at an integrative medicine clinic, the responses were similar. Adults reported significant decrease in pain, better sleep, increased mobility and overall feelings of relaxation and serenity. While staff at GMCH had a general awareness that warm water was helpful for the children, I think it was these initial observations of medical staff, volunteers and family members that supported the development of a more formalized program.

III. What we do

In essence, our hydrotherapy program has a dual focus. One aspect is similar to that of the Special Needs Aquatics Program developed in Berkeley, CA, by Dori Maxon, PT, MEd, PCS (www.snapkids.org). I have been volunteering in this program for over eight years. Thanks to her training I have been able to implement many aspects of Ms. Maxon's excellent program at GMCH. Although our pool is very small we are able to help the children kick, move their arms, do swim strokes, throw balls, play games, vocalize and become stronger. There is no end to the surprises we receive from children who live with major health challenges. Ms. Maxon and I continue to collaborate in training staff and volunteers for the GMCH hydrotherapy program.

The other aspect of our program has been described by Program Director, Judith Dunlop, MA, MDiv., as "the quiet work." Gently, quietly, with great attention to detail, children who are profoundly challenged, medically fragile or at end of life are floated and moved in a serene aquatic environment. Sometimes we play music; sometimes we enjoy the soft sounds of the water lapping at poolside. As each child is unique, so each session is unique. Sometimes I am accompanied by one staff or volunteer. Sometimes a parent or family member(s) participate(s) in a session. What is most essential is to be aware and totally present to the child in the moment. At all times the child.



V. Effects of hydrotherapy on the child

The following story describes one child's response to her first hydrotherapy session.

The Light of Lucia

Lucia has beautiful eyes and a dazzling smile. She is very bright. Lucia is bilingual in English and Spanish. She has spinal muscular atrophy in an advanced state. One day I took Lucia into the hydrotherapy pool. It was only the second time in her life that she had been in a pool. The water felt very warm to her, but she got used to it and found it very relaxing. Lucia smiled her dazzling smile and exclaimed, "I feel like I'm flying."

I promised I'd hold her and keep her safe. Lucia realized she could move her arms easily in the water. Then, for the first time ever she moved her feet and legs, just a tiny bit. She asked if I could hold her by her head only. I put a little floater under her knees for support and carefully held her head. This allowed her more independence. Just before we ended, I held her in my arms and floated her briefly. She looked up at me with the most loving smile and said, "This is the happiest day of my life!"

The water can have profound effects on hydrotherapists and families as well, as this experience indicates:

Letting Go

It seemed as if we were never going to be able to take Nia into the water. A delay had occurred in obtaining signed consents allowing her to participate in the hydrotherapy program. I was worried because I saw Nia begin to decline. She became increasingly unresponsive. I knew she was preparing to transition soon.

Ultimately, the consents were signed. We prepared to take Nia into the pool for a session. My nurse colleague and a volunteer assisted me as we gently lowered her into the warm pool. Her Mom sat on deck watching us. We did not know how much she really understood of the finality of Nia's journey. Nia's Mom watched us for a time, then left. We understood she needed frequent breaks.

The love, tenderness and gentleness were palpable as we worked with Nia, gently massaging her, moving her through the water, speaking to her softly. Finally, we gently lifted her from the pool, patted her dry and returned her to her room.

Later I spoke to my colleague who helped me with Nia.
"I still don't know if we accomplished anything. Nia seemed very deep in coma."
My nurse friend replied simply, "We helped her to let go."
Forty-eight hours later, Nia died.

In between patient sessions one day, my nurse colleague and I were sitting at poolside taking a little break.

"Our work is different now than when we first started," she said.

"How is it different?" I asked.

She responded, "Now, we let the water do more of the work."

This brief comment speaks volumes. In a palliative care setting, there is no need to "demonstrate patient progress," or to "show improvement." When we let the water do more of the work we simply *are* with the child in the moment. We certainly use the best techniques available to us. We encourage the child to



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participate in activities and attempt new tasks. We allow ourselves to *be surprised* by the child and to *rejoice* in any accomplishment, no matter how small. Mostly, the children radiate joy and peace. It is our privilege to mirror those emotions to others. The entire staff of GMCH is exploring new territory by offering hydrotherapy for medically fragile and end of life children. I have never experienced such support and collaboration. Staff is always there to prepare the patients, help with showering, lifting and transport. I enjoy it when they can stay and observe.

I find this work in warm water to be a humbling work. As I peel back the layers of meaning of my work in hydrotherapy, I notice I have acquired a deeper understanding of many dimensions of palliative care. I am forever moved by the trust of a child as she allows me to move her through the water. I never leave the water without realizing how little I really know. In my entire career I have never felt more like a nurse than when I work in water. This work calls on all the skills I have ever acquired while reflecting the truly holistic nature of nursing. We support the little physical bodies, allow full expression of emotion, encourage their minds to experience new sensations, and nurture the spirits of those who are preparing to fly free.





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GENTLE NOTES: MUSIC'S ROLE IN PEDIATRIC PALLIATIVE CARE AND HOSPICE

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A touching, hand-written note arrived in my mailbox: "My beautiful baby girl couldn't hold onto life and I had a lifetime of hopes and dreams for her, much more than her five precious days. The moment that I felt most spiritually connected to her and God was when you played the harp in the neo-natal intensive care unit (NICU). While you played, I took a brief respite from all the decisions that had to be made and the music helped me to relax and focus on the present moment. This was a transformational time for me when it became clear that I must let her go and she would be eternally safe."

As a therapeutic harpist playing in several children's hospitals in the Minneapolis and Rochester, MN area, I see how the harp touches children and their families at this painful, yet often, beautiful time of palliative care and in hospice. Music's gentle notes can 1) comfort during the heightened stress of pain, serious illness, and end-of-life care, 2) create an environment—an intimate space—for the transitioning child, the family, and the attending medical staff, and 3) add richness, depth, and tenderness to the sacred experience of dying.

Music comforts during the heightened stress of pain, serious illness, and end-of-life care

I was asked to play for a two-year old boy who was dying of a rare heart disease. I introduced myself to his parents before I started playing. As soon as I began, it felt like all the tension melted out of the room. The music seemed to be *comforting* to all and connecting in a deep way with each person present. I played for 30 minutes and as I moved my harp out of the room, the parents followed me to the hallway and said, "When dear friends found out we were pregnant, they gave us a children's lullabies CD called *Cradled on Wings of Love*. Is this your CD?!" I said, "Yes!" They continued, "We have listened to your CD a lot—through the pregnancy and during the delivery, plus every night since John was born, and we even have it with us in the hospital! From the moment you started playing today, we felt a familiarity and we could sense it in our son, too. Unfortunately, we know our son isn't going to make it. But our connection with him today was so full of light as you played. We will always cherish this memory and whenever we want to feel his angelic presence, we will play your CD." This is an example of how comforting music can be when it is played live, as well as using recordings at the hospital and hospice bedside.

Music creates an environment—an intimate space—for the transitioning child, the family, and the attending medical staff.

Melissa was 14 years old and was dying from brain cancer. The cancer had spread so much, the doctors could no longer operate. As the chaplain and I walked onto the pediatric intensive care unit (PICU), we were met by Melissa's parents. I felt an immediate connection and fondness for them. Her dad informed us the medical staff were going to withdraw her from the ventilator later that afternoon. I was touched by his openness, candor, and sincerity.

I set up my instrument and began playing softly. Melissa's parents and aunt took turns speaking to her and gently stroking her face. Something beautiful was happening in the room. There was an incredible feeling of *love*—love coming from every person, spreading into every part of the room. Instinctively, those present knew to support and care and attend to each other and to Melissa as they said their good-byes.



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Melissa looked relaxed, calm, peaceful, content. She was filled with love and radiated “all is well with me.” Everything (medicine, prayers, speaking, and touching) that could be done had been done. Music was the final gift perhaps touching her where nothing else could and giving her family comfort seeing her in such peace and love during her last minutes. The music softened the environment and was an important part of the family's closing ritual where love, in its most beautiful earthly form, was present.

Music adds richness, depth, and tenderness to the sacred experience of dying

Music allows all of us (the children, loved ones, and professionals) to connect with our hurting hearts and “gives voice” as we say good-bye. After dear friends lost their beautiful newborn daughter, they asked me to play the harp at her funeral. It was an extremely sad occasion ... every note, every chord brought tears and pain. As a collective, grief-stricken community, we recognized the music was taking us to our deepest wounds of sorrow. It was important for us to acknowledge this pain—a time for one final connection with the angelic little baby lying in front of us in her long, flowing, white baptismal gown. Later, one of the family members told me, “We were so deep in our pain during the memorial service, but at one point, I saw angels all around our baby Caroline. The music helped facilitate this incredible vision ... I know Caroline was lifted to the heavens with ethereal music and she is safely protected forever.”

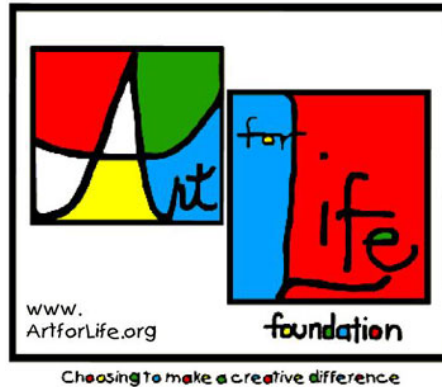
In closing, Mother Teresa said, “I have found the paradox that if I love until it hurts, then there is no hurt, only more love.” Music's gentle notes speak to our hearts and expand our love so that we can be more present and of greater service to the transitioning children, the families and loved ones, and the other healthcare staff. May music help you release the hurts and expand with love in this special field of pediatric palliative care and hospice.

Reference

Briggs, T. (2002). *Grace Notes: Reflections on the Harp and Healing*. St. Louis Park, MN: Musical Reflections Press.

Note: Additional information about the “Cradled on Wings of Love” CD and other CDs suitable for use with children and families is available from the website in the heading of this article.

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ART FOR LIFE – CHOOSING TO MAKE A CREATIVE DIFFERENCE!

Anthony Knutson
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"When children of any age enter a hospital, they become part of a group that is defined by illness and yet when they enter a place in the hospital where art is created, they become part of a group that is defined only by imagination. They become part of a nurturing environment where they can express themselves freely. Art provides a passage of joy that allows children the chance to transform their lives on their journey from illness into wellness."

Founder- Anthony Knutson

Over ten years ago, sitting wrapped in the warmth of the Impressionist room at the National Gallery in London, I watched others enter to take refuge from a wintery and foggy London afternoon. The room vibrated with a calm and soothing energy. I watched everyone's faces relax and sensed their energy shift from frenzied to calm as the impressionists' work moved through their souls. It was inside of that moment that I understood that art at its deepest level was about healing. When people in that room saw Monet's paintings, it wasn't just how the paintings looked that drew them close, it was how they made them feel and how they made them feel was healed. Today, we have learned that not only can we get value in healing from a completed piece of art, we can get tremendous value in healing from the creation of art. Art can play an active role in our lives. Self-expression through art can heal us.

I believe we each have a purpose in life. If we pursue our passions, that purpose will find us. Therefore when I decided to create a nonprofit it was important for me to work in three areas that I was most passionate about: children, art, and healing. I wanted to focus specifically on children who are hospitalized or in various stages of illness, facing end-of-life issues, or in some kind of physical or



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emotional crisis. I wanted to bring them the creative process and allow it the chance to help them heal. Kids intuitively know that art heals. Adults fight the concept and require outcomes for proof—kids don't. Kids tend to value imagination and the creative process placing them on the same level as everything else in life. They know that they can express how they feel through art and they do so with a raw honest insight. They may not understand the language that art is a form of therapeutic healing; they just know it is fun and that it makes them feel good!

I recall the story of one young boy who would routinely start getting sick in the car on the way to his chemotherapy treatments and stay sick through the treatment. Then we introduced him to art and the promise of art through the course of his treatment. He no longer got sick on the way to the hospital or during his treatment. Art had transformed him and the room where he was being treated. The creative process of doing art and having fun creates a healing environment.

One of my favorite pictures created by a young girl in one of our hospital programs is of a simple house with three windows. Two windows have bright yellow curtains and one window has black curtains. When asked to explain the reason for the difference in color, she said "one room has cancer." Can you guess which room it was? And can you guess whose room it was? I'm not certain of the outcome of that girl's illness; however, I know in my heart that her expressing it through art had an empowering effect on her. Art gave her control in a situation in which she must have felt out of control. Kids don't just do art, they live within it. They take a crayon and a piece of paper and create a world that is real and in that reality find a place to heal.

The purpose of Art for Life is to help kids to heal physically, emotionally, or mentally using art and its creative process: art and children working together, creating together, and healing together. The benefits with working in all of these areas are that they allow art to be a part of each aspect of a child's life when he or she needs it the most. Over the years we have developed several programs that work in both partnership and supportive roles with children's hospitals and facilities that treat children who are in need of healing physically, emotionally, or mentally. Our award winning *Art While You Wait Program* reaches children through emergency rooms and clinical waiting areas where art helps ease the fear of being in the ER and helps in pain management. *Art to Go* provides a creative project that a child can look forward to doing after difficult treatment or, as we say, for art when *they feel like it!* Our *Coloring Books, Crayons & Kids!* Program is offered in a room operated by a victim assistance program in a courthouse where family struggles often find kids placed into foster care. *Vickie & Friends* and our *Ceramics & Kids!* Programs use ceramic pieces as the inspiration and focus of the creative process.

Our *Artfelt Moments* and its *Tiles & Tales* Program are designed to support hospice care. *Artfelt Moments* works with terminally ill children and their family and siblings, giving them the chance to create art together for fun and for legacy pieces. *Tiles and Tales* offers families, friends and relatives the opportunity to find healing in creating a memorial tile to honor their child that has passed. The tiles created in our *Tiles & Tales* Program are given a place of honor on our Children's Remembrance Wall located in a hospice facility. I remember personally working with one teenage girl in hospice care making handcrafted ceramic pieces for each holiday. Per her request, after her passing I delivered them to her family so that she could continue to be a part of each holiday. *Studio:Art!* offers art projects in a monthly pediatric cancer support group that includes a personal gallery display in the hospital so kids can create a fun space inside one usually filled with fear. This program also has an ongoing commitment to the kids to be there every month so they can count on us to help them express themselves through art. *Feeling Notes* takes the healing journey of art into music with a talented harpist, while *The Art of Children* gives the art created in our programs a chance to be seen in a public setting. In every one of our programs not only do the children benefit but the families, siblings, and staff do, as well, as they transform the environment that they are in into a rich creative vibrant energy that is filled with joy and color.



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For over ten years Art for Life has been there for children helping them to heal through art. When we began we had one small program in one hospital helping a few kids a month. Now we have twelve programs in eight states and help over twelve thousand kids a year. And we continue to grow. Our Art for Life programs have become an integral part of several children's hospital services and are recognized throughout these organizations as an important adjunct to educational, developmental, recreational, and psychosocial support services. Our programs provide inclusive, interactive, therapeutic art activities that help normalize the hospital experience for kids. All kids are encouraged to participate, regardless of physical limitations. Our programs work either in a group environment or in one-on-one sessions with the objective to provide a nurturing and inspirational creative experience to every child. Not all of our programs are in children's hospitals; however, each of our programs work with ill children using art as an effective tool—empowering them and often times their siblings and family members to actively participate in their own healing process. Helping us reach kids everyday in every one of these programs is our network of volunteers. They are the very heart of our work and we are grateful to them for sharing their valuable time to help us make a creative difference through the creative process in the lives of sick children.

At Art for Life we focus on healing children with art, however art as a valid healing modality isn't just for kids. Our foundation believes it is in our spirit and our ability to use imagination and self-expression through art, that each of us can find healing and in that healing, heal everyone and everything around us.

Art, if we allow it, can wrap itself around us like a warm blanket and offer us comfort through self-expression. It can also mold itself to us like a suit of armor giving us strength and protection for those times when we need it. Allow art the chance to give your creative soul life. Embrace an understanding that art is how we each express ourselves in the world and through art we can actively participate in our own healing process whether it is physical, emotional, or mental.

“Art is the rainbow that appears after every storm, reaching out, inspiring, transforming, and reflecting back the love and life of everyone it touches.”

Anthony Knutson



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Art for life is a 501c3 nonprofit and is fully supported by donations. Help us to continue to reach out and heal children with art. Share the dream. For more up to date information on all of our programs including how you can help, please visit us at www.artforlife.org. You can help us make a creative difference in the lives of children in physical, emotional, or mental need.

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THROUGH MY LENS: MOMENT BY MOMENT

Karen Henrich
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As a photographer, I capture images of children through my lens. You see them through my eyes. You see freckles and bruises, tears and giggles. But it is through the eyes of these children that we all can see truly important moments and the appreciation that they have of these moments. To see the world through the eyes of a child is to see the world filled with wonder, joy, excitement, love, purity, peace, curiosity, and even defiance. I believe that all children are full of this same wonder of the world; it evolves from within and is visible whether they are healthy, as we are so blessed that most of our children are, or ill.

I have started a non-profit, Moment by Moment (www.momentbymoment.org), which captures images of terminally ill children and presents their families with keepsake portraits. A cadre of professional photographers donates their time to work with the foundation to capture these precious images. Together, we have found that the spirit of a child does not hide in their illness; through our lenses, when pointed at these courageous children, we capture hope, determination, and the connection of a family. We capture those wonderful moments and looks that parents may take for granted or may, in the future have a difficult time remembering.

The first question that I often get asked is, why take portraits for a family when their child is sick? No one of us knows what our tomorrow may bring and yet all of our tomorrows will include birthdays, holidays . . . and more so than ever these families want to document and celebrate what they have each day.

Realistically, it is my blessing to work with these families. I reflect after each shoot how blessed I am today that I did not have to comfort a child in pain. Today I did not have to meet with a team of specialists, who, no matter how much training they have, still cannot tell me for certain that my child will be "fine." Today I did not have to spend the day with my child in the confines of hospital walls, not be able to just go to the park and play. Today, I am grateful that I can afford the time for the luxuries of a workout or coffee with a friend without the feeling that I should instead be at my child's bedside. Tonight I will not have to sing a lullaby and say prayers with my child in a hospital bed. Today, just for this moment, I am grateful to be on the outside as a photographer capturing these precious moments of a family that will translate into irreplaceable memories of a child who will make an indelible mark on this world, no matter how long he or she is in it.

I go home from each shoot and tell my two boys how much I love them. Inevitably, the response is, mom, we love you more. I explain that cannot be possible. But again, for today I am very grateful for the moments that we have.

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WITNESSING WORDS: WRITING AND PALLIATIVE CARE

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As a medical student, I knew that conquering facts, figures, and skills necessary to cure disease and “save” lives was essential. I also anguished over what I would miss if that conquest were my only focus. I reflect back on my meticulous dissections and memorizations in anatomy labs and realize I emerged with only partial insight into the configuration of the human body. Years later, Kathleen Metcalfe’s poem, from her 2003 collection **Signs of Life**, deepened my understanding:

Lub DUB

I disagree with anatomy.
I know for a fact that
A heart can be found
In a throat
At the bottom of the stomach
Perched on a sleeve.
I know it can freeze
In the icy pericardium of winter,
Thaw in the spring of new beginnings.
I know it can be
Lopsided as a kid’s valentine
Big as the universe
Absent as the tin woodsman’s.
I disagree with anatomy.
I know for a fact that a heart can
Rub
Thrill
Split
Almost give in and quit.
Yet hearts, great hearts, my friend
Can mend!

With words, music, pictures, and a myriad of other expressions, art accompanies medical experiences and invites us to explore the deep undercurrents of life, illness, death, and healing. We must bring the best of our knowledge and expertise to our hospice and palliative care practice, but we miss so much



when we limit ourselves merely to interpreting lab values, reviewing scans, calculating dosages, and writing prescriptions. When we restrict our focus, we may feel only the defeat of disease and overlook the pockets of spirit that inspire courage and resilience—not only our own but also our patients' and families.' When we compose our poems and hear our patients' stories, we can listen deeply to the tones of despair and hope, fear and trust, rage and joy. We can enrich our perspective and help navigate not just the terrain of pathology but also the landscape of illness and grief.

Seventeen-year-old Caitlin Dolaghan was a writer. In the midst of her battle with osteogenic sarcoma she affirmed beauty as she wrote in her journal:

The moon is beautiful tonight. It's not a full moon, and yet it still shines brightly. It shines what it can. I have many things to complain about but I just don't feel like complaining at the moment. The stars and the moon are out, and they are so enchanting. I do feel like a princess... but I don't know if this fairy tale will have a happy ending. I love being a princess, one who fears nothing. I am so used to feeling my spirit sink. It's a nice change to feel happy, and over something so simple as the moon. I love the night sky. I don't want to close my curtains. Why do people associate the night with evil? It's beautiful. The creatures of the night aren't evil, they are graceful, they can move silently in the dark.

Fifteen months before her death, her father, John, discovered the writer in himself when he expressed his anguish, coupled with hope, in his first poem for Caitlin:

I walk with my daughter
 in the valley of the shadow of death...
I need words of courage as
 the shadow of death falls on my daughter's face...
We rest by the path,
 I listen to her hopes and dreams,
In this shadow that swallows hope,
 and makes dreams dark.
When death's shadow was distant
 I seldom heard her dreams.
She mourns her deep loss,
 I share her tears of pain...
We will emerge from this shadowed valley,
 Held firm in our Father's heart.
We will be together,
 Whether we travel on together for a time
 Or for a time, our paths diverge.



Writing together in a family circle invites the possibility of discovering together vulnerabilities and strengths, trusting shared expressions, and restoring relationships so easily shattered when disease dominates. In an exercise inspired by J. Ruth Gendler's **The Book of Qualities**, Caitlin wrote about despair:

***Despair** is an old tigris. She once was strong, but now has seen all the horrors of reality. Her stripes make it easy for her to hide from those who want her gone. She stays with those who feed her, but out of caution she lashes out at them, sometimes taking an arm or a leg of them. This makes her bigger though she does not want power. She hates her self for existing, and yet she still tries so hard to stay alive because she's afraid of not existing.*

John, her father, introduced despair in this way:

***Despair** is a small stooped gray man. You might see him with the homeless vet in the park. He is often with those who have sold their souls for things. Don't be deceived, though. He has great power, and he watches you. When he speaks his words can drive into your center and lodge there. They freeze your soul. If you let despair speak to you he will transform you into a cheerless, grumpy, smelly person who has forgotten what it means to live. Despair is a recluse. He hides in the corner at parties and never shares a toast or a drink in celebration.*

Wilson, Caitlin's brother, described confusion and happiness:

***Confusion** is easily made and released. It bounces in your head ricocheting off your skull destroying your thoughts.*

***Happiness** lifts your head and pushes all bad things out your mouth. It spreads through your chest and arms to break you free.*

Peggy, their sister, personified disappointment and joy:

***Disappointment** lives downstairs and I have to pass him on the way out. He doesn't say much, just reminds me that he's there. Sometimes he stands outside my door. I tell him I'm really busy and we'll talk later so he goes downstairs and sits in the lobby and waits for a better time.*



Joy may talk a lot, but I don't mind. She knows the best stories anyway. She showed me a bird's nest once and gave me a piece of blue sea glass at the beach. Her eyes are ever so keen.

Carol, their mother, wrote this about joy:

Joy isn't happiness. She isn't everything going swimmingly. Joy comes from truth and hope and knowing you are loved.

Joy wakes up early in the morning, goes outside and listens to the birds in the morning quiet, and then has the strength to go on and look into the face of tragedy and suffering.

Before Joy came into her own she was always disappointed and angry at the world, but now she has a foundation, a timeless underpinning that keeps her anchored in the truth of God's unfathomable love for her.

And, as part of their circle, I had also written about joy:

Joy doesn't always wear purple, but she does today. She's wanting to wear something rich and deep so she won't be confused—as she so often is—with her second cousins happiness and acquisition. They often wear royal blue, which Joy would wear too, except she knows it's important that she stand out more on her own. She's the one who can always be available. Even if you can't find her at home right away, you can check with Gratitude. Gratitude always knows how to find Joy.

Joy can walk arm in arm with profound Sadness, with setbacks and frustrations, and she generously invites Hope to accompany her on many of her journeys.

More than two years after Caitlin's death, writing has continued to link feelings, experiences, meaning, and people in her family and community.

With a prompt of 'it matters,' Wilson wrote about his volunteer mural painting:

It matters. One reason I felt that painting murals at the orphanage in India was important was because I thought of how a new kid who had just lost his or her parents



would feel their first night in the orphanage, and I thought of how pictures comforted me as a child. They could imagine the animals walking around and keeping them company. They need comforting and it's a way that I can give it to them.

Responding to "I've learned" he wrote:

I've learned that I can't be comforted by microwaved religion anymore.

I've learned that almost everyone has known or will know pain like this at some point in their lives.

I've learned that people don't want to hear about pain or suffering unless it is connected to them.

I've learned how bad it feels to really lose someone.

Peggy reflected:

I've learned

Not to linger on those thoughts

Those memories of what I could have done

Not to zero in

Microscopically

Paring away wasted moments

*Till I'm left with what I thought was
Important*

And the dross of the everyday lies in a heap.

I've learned not to

Because I know I miss the everyday too.

Hearing her in her room

Or hunched over a drawing that will inevitably have a story.

The exasperation and amusement

Her picky eating caused.

The annoyance and yet not annoyance of hearing her tell

The same funny stories over and over

To anyone who would listen...

I miss

Because it is her...



Elise Hubbard, Caitlin's best friend, shared:

I've learned that we are strange creatures of habit. That if something falls out of place, we panic. That if something is out of the ordinary, or it is out of our comfort zone, so to speak, we avoid it like avoiding the wrong side of the freeway.

Knowing Caitlin has been a life-changing event. One of the things I learned is that most things we usually fret about in life just don't matter. Really.

Carol mourns the loss of her daughter in her poem "Lament's Regret":

*I'm left with memories, mementoes
And with a mother's regret
Of a well-ordered life.
We could walk across the kitchen
Our bare feet never sticking
Not a single Grapenut to trouble our soles.*

*And you on my lap
A maple leaf in your hand.
"See, it's sliver," you said, stroking the underside.
But I was a step ahead of myself
Wondering what I would put in the night's stew.*

*If only
If only
If only
If only I could steal back
Even one of those days
Or an hour
Or a moment
Before you crossed the thin silk strand
I could weigh your graceful hand in mine
Look into your face until I saw your dreams
Play into your eyes*



*Saving you from the loneliness of having
A mother who cared more about vegetables
Than a maple leaf with a sliver underside.
Write it small
But scratch it deep
There was a promise
I couldn't keep.*

We can collectively witness the hopes, heartbreaks, and wonders we encounter in end-of-life care, from sharing the delight of cherished stories and songs to soothing sorrows when we write together with families. We may find our best voices as well by expressing heartfelt wishes as I did in this piece I wrote at a patient's bedside with one of our Comfort for Kids families.

I wish

*This may be
The hardest time
You ever face.
And that
Courage
And kindness
Compassion
And love
Warm memories
And the making of
New ones
Will carry you
Always.*

As we encourage our patients and ourselves to engage in life artfully, we each rediscover and nurture connections with our own inner resources and may expand our horizons to truly practice the art of healing.

What If

*What if
We invited
Humility and wonder
To walk
Hand in hand*



*To say
'I don't know'
Not with apology
But with awe and appreciation
Of this great universe
Bigger than we are
And with anticipation
That accompanies
'We can explore'*

*What if
We didn't insist
That miracles
Big or small
Be constricted
And defined
Miniaturized
So we can understand
And control
And get them authorized*

*What if
We didn't insist
On understanding
Accepting instead
That it's all right to know
Inside*

*What if we allow
Experience
And growth
And trust
And raw enthusiastic appreciation
More than*



Judgments

And control

And power

And things

What if

We listened

To 'can' and 'will'

And hope and joy

Rather than

'Can't'

Or 'won't'

Or discouragement

Or despair

What if

We chose to

Regard life

As a wondrous

Joyous

Experience

Rather than

A measure of

Productivity

Accomplishment

Achievement

What if

We stretched the barriers

So thin

That we could see through

To the other side

With fullness

Instead of strengthening those barriers

Nurturing them with our



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Limitations

Doubts

And fears

What if

We just

Love

A lot

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A REWARDING EXPERIENCE: A TEENAGE VOLUNTEER'S REFLECTION

Maeve Gallagher, Teen Volunteer
Hospice of the Western Reserve
www.hospicewr.org

Hospice of the Western Reserve has had a formal teen volunteer program for almost ten years now. We accept teenagers from the ages of 13 to 18 years and have one full-time volunteer coordinator; who is in charge of the education, recruitment, supervision, and assigning of the teen volunteers. The teenagers support our mission at all levels in the agencies. The following is Maeve's reflection on the meaning of being a teen volunteer with the pediatric patients and families.

I have been granted one of the most rewarding experiences through working with Hospice of the Western Reserve's pediatric patients. I didn't realize it at first. It was after I was given an assignment at school to write about my spiritual journey that I began to understand how working with children who are dying has impacted my life. Through my experiences I have grown in multiple ways. The patients that I serve teach me that each day is a blessing and not to be taken for granted. They touch my life in more ways than one. When I am with them, it feels as if the hectic spin of my everyday life pauses to focus on the needs of the small child. I try to give every ounce of love within me to the children and make sure that they know that they are loved.

It is not easy to know that these wonderful little angels' lives are inevitably cut short. My goal is not to focus on the fact that these children are here for a short time but that their time here on earth should be as memorable as possible. My volunteer work at Hospice helps me to take a step back and give to others who are less fortunate and are on their final journeys.

The feeling that I get when holding the babies who are dying is that they are completely real and unaffected by the material things in the world. I am fully aware that my spiritual journey is nowhere near over. I plan to continue my work as a volunteer focusing mainly on pediatrics. It is extremely hard to see such an unfortunate situation unfold, yet amazing to know that these small children have touched my life more than anyone will ever know. The memories I built with these children, the warm feeling it gives me when I hold them, and merely spending time with them will never leave me. These patients have forever changed my life.

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Items of Interest

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

1. Pediatric Standards Now in Field Review Process. NHPCO's Pediatric Standards are available for review and comment beginning August 14, 2008. The review and comment period will be open until **Friday, September 26, 2008 at 5:00 pm ET**. The review of the Pediatric Standards is open to all interested participants. NHPCO members and others are encouraged to disseminate the announcement of the Pediatric Standards Field Review Process and encourage all interested stakeholders to participate. Following the close of review, all comments will be reviewed and assessed by ChiPPS, then sent to NHPCO's Quality and Standards Committee for final approval. NHPCO gratefully acknowledges the work of the ChiPPS in developing the Pediatric Standards and to Susan Huff for leading the project. Questions about the Field Review Process should go to quality@nhpco.org. Go to the Quality Partners section of NHPCO's Web site to participate in the [Pediatric Standards Field Review](#).

2. Pediatric Intensive at NHPCO's Clinical Team Conference (CTC). NHPCO in collaboration with ChiPPS is proud to have created a *Pediatric Intensive* which includes a preconference seminar and an educational session track that is part of NHPCO's CTC being held in Dallas, TX, Oct. 22-25, 2008. To download the conference brochure and/or register online, visit www.nhcpo.org/conferences.

3. NHPCO and ChiPPS Pediatric Listserve. NHPCO and ChiPPS have created a special pediatric listserv for NCHPP or eNCHPP members who provide services for children with life-threatening conditions and their families. [Read more](#) the listserv and eligibility requirements to participate. [Join the Pediatric Listserve](#).

4. Subjects and Contributors for Future Issues of This Newsletter. In past issues of this newsletter, we have addressed a wide range of subjects, including bereavement, sibling bereavement, self care, ill and dying teens, perinatal loss, neonatal loss, spirituality, and unsung heroes in the circle of care. In the immediate future, we are considering an issue on **pain and symptom management for children with life-threatening illnesses and their families**. If you know of good topics and/or contributors (including yourself) for this and other future issues of this newsletter, please do not be shy! Step right up and contact any of the following: Christy Torkildson at torkc@sbcglobal.net; Mary Kay Tyler at mktyler@hospicewr.org; or Chuck Corr at charlescorr@mindspring.com. We will work with you!

5. 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.

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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.

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.