ChiPPS Pediatric Palliative Care Newsletter
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Edited by Charles A. Corr, PhD, CT, Christy Torkildson, RN, PHN, MSN,
and Maureen Horgan, LICSW

Issue Topic: Complementary Therapies in Pediatric Palliative Care (Part 2)
(First part addressing this issue was released November 2009)

Welcome to the eighteenth 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 second of two issues in this topical area. Issue #17, published in November, 2009, also addressed this subject and can be found among archived issues of this newsletter at www.nhpco.org/pediatrics.

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.

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.
Issue #18: Complementary Therapies in Pediatric Palliative Care (Part 2)
(Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.)

Jordan’s Inspiration  p. 4
Nanette Ray
Nanette courageously shares her story of her son Jordan’s battle with Osteosarcoma, the use of complementary and alternative therapies, and the struggles faced by her family. At first complementary and alternative therapies were used alongside traditional therapies as a way to help deal with the side effects of treatment; in the end they provided a way to grow and gain strength spiritually.

Self-Discovery  p.6
Jordan Ray
In this essay Jordan shares his own thoughts on his journey and the spiritual growth he experienced. A remarkable young man whose words will touch you.

Complementary Therapies: A Journey from Professional to Personal  p. 7
Lisa Buell
A frequent contributor to our newsletter, Lisa states that “balancing eastern and western medicine enabled us to fully appreciate and participate in the life we had with our child.” As a licensed and certified massage and Reiki therapist Lisa brings two perspectives to us - as both practitioner and parent.

CAM: Dietary Supplements  p. 9
Constance (Connie) Bergh, MSH, RN
Connie provides us with an excellent brief review of the literature on complementary and alternative therapies. As stated in the piece, this is a growing field and every healthcare professional should have a basic understanding of complementary and alternative therapies. This article will help and the extensive reference list and links will guide you to more information.

Promoting Health through Creativity: Supporting the Emotional Needs of Hospitalized Children and Their Siblings through Therapeutic Activity Books  p. 14
Steffanie Lorig
Every pediatric waiting room I have ever been in has expressive play areas, whether chalkboards, whiteboards, or coloring books and crayons. As a mom, I always carry a box of crayons and a pad of paper. Experientially we know that art has a healing effect. Steffanie took this knowledge and the growing literature in the field and founded "Art with Heart." She shares her experiences as a child with frequent hospitalizations to the children who helped focus her energies to creating tools to help children of all ages.

Inside the Kids Path Garden: Healing Gardens Offer Support for Children Who are Grieving  p. 18
Sally Cobb
Sally provides us with a wonderful look at horticultural therapy. As she states, "Simply viewing nature’s splendor may allow us to begin to relax and unwind. Through nature, feelings of comfort may be experienced amid the feelings of grief.” Take a tour of the "Kids Path Garden" at the Hospice and Palliative Care of Greensboro, North Carolina, that Sally has provided for us!

Specially Designed Music in Health Care: An Interdisciplinary Research Project  p. 20
Inge Mulvad Eje
We are very proud to provide you with this article from Inge Mulvad Eje, musician, producer, and project coordinator in Denmark. Inge provides a brief review of the literature on music therapy and shares the findings of a very special project focused on music. She describes this research as "a project founded on the known fact that music can have a significant positive effect in many treatment situations."
Lay Your Hands on Me: End-of-Life Light Touch Therapy for Seriously-Ill and Dying Children  
Maureen Horgan, LICSW, and Ann Fitzsimons  
Maureen and Ann provide an overview of light touch therapies such as Healing Touch, Reiki, and others. The authors also provide us with practical suggestions on how to incorporate these therapies in the care of the child and family.

Annotated Bibliography: Light Touch Therapy  
Kate O’Sullivan† and Maureen Horgan, LICSW  
Kate and Maureen provide us with an extensive annotated bibliography to supplement the previous article on Light Touch Therapy.

Pet Therapy and Pediatric Palliative Care  
Pat Frasca, MA, CCLS  
Pat, a child life therapist who is also guardian and best friend to therapy dogs, provides us with an overview of pet therapy and a look into the life of one special little girl and a dog named George – the unusual therapy dog. You will also meet Trevin, therapy dog with the exceptional demeanor and wardrobe….. As noted by one pet therapist friend and guardian, “During my journey of awareness of pet therapy and the impact it had on the patients, I came to realize that the visitations were just as therapeutic for the staff as they were for the kids.”

What is ChiPPS and How Can I Get Involved?  
Mary Kay Tyler, RN, CNP  
ChiPPS Co-Chair Mary Kay Tyler invites interested individuals to become involved with ChiPPS.

Items of Interest  
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.
JORDAN'S INSPIRATION

By Nanette Ray
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My son Jordan was first diagnosed with osteogenic sarcoma in his right knee and partial femur in May of 2004. He was 15 years old and had just finished his 8th grade school year. It was my father who suggested that he take certain vitamins and essiac tea to help him get through the effects and damages that chemo causes. Unfortunately the treatments for cancer are like a double edge sword. You need them to try and kill the cancer cells, yet the chemo and radiation can also damage the organs. It was my father's belief that taking these vitamins and drinking the essiac tea would help to support his immune system and organs as well as help to conquer the cancer. It was he that ordered all the vitamins and would make the essiac tea and send it to me, since he lives in Hawaii.

At first, Jordan wasn't too keen on having to take so many different vitamins and really did not care for the taste of the tea. But within a short time we saw how much of a difference it made. We were able to keep him out of the hospital when he went neutropenic when he should have been admitted.

The first validation came when I was told by a veteran nurse that Jordan would be back in the hospital because his immune system would be greatly compromised. All the children end up having to be hospitalized once they go neutropenic, especially because of the high doses of chemo he was receiving intravenously. They were rotating treatments of Cisplatin, Methotrexate, and Doxorubicin. It was with great pride when I proved the nurse wrong: Jordan didn't have to be hospitalized, even when he had his surgery to replace his knee. I was amazed at how well he was able to recover so quickly.

When he had to resume his chemo treatment about a month and half later, he went neutropenic very badly this time. Jordan ended up in the hospital for 10 long agonizing days filled with so much pain and suffering. He had gotten mouth sores, more than we could ever imagine. They were all over his lips throughout his whole mouth, going down his throat and coming out the other end. I couldn't understand why at first; I thought maybe the chemo had taken its toll on him.

It wasn't until after he had gotten out of the hospital that we found out why: Jordan had stopped taking the vitamins we were giving him, hiding them in his room and trash can. My father found the ones in the trash can when he went to empty it. To say the least, we were angry at Jordan, wanting to know why he stopped taking them. He said whenever he would tell his father that he believed the vitamins were helping him, his father told him that it was all in his mind, that the vitamins weren't doing anything for him.

I was so angry at both of them. All Jordan could do was cry and say he was sorry, he didn't know, he thought maybe his father was right and that it was all in his mind. Unfortunately Jordan found out the hard way and from then on he always took the vitamins. He did end up going back into the hospital a couple of times after going neutropenic but each time it was for less days and not as serious as the first. Thank God, Jordan ended up going into remission for about 3 years. Due to certain circumstances beyond my control, Jordan and his younger brother had to go and live with his father in Virginia as soon as his port-a-cath was removed.

We all know how important it is for a person to be screened on a regular basis for cancer. While Jordan was in Virginia he did have his scans done. But as soon as he turned 18 years old he returned back home to Florida. At that same time he was due for another scan, but his father refused to change Jordan's address information back to Florida. By the time we were able to get the address changed and appointment set up, Jordan was behind almost nine months for his last scan. That scan showed that the
cancer had come back with a vengeance: six tumors, three in each lung. We got the news of his recurrence the first week of November, 2007.

His first lobectomy on the left lung was the day after Thanksgiving. Instead of finding three tumors, they found between five to six tumors. The second surgery for his right lung was January 2, 2008; instead of the three, they found five tumors and also the tumors returned on his left side, and one was close to his heart. When the surgeons came out they called us to a room and let us know what they had found. It was then that they informed us that his 20% chance of survival just became zero. It's hard enough to be told that your child has cancer and he may or may not survive, but it's even harder to hear that there is nothing more they can really do medically, and to have your child be told that he is going to die, and there is nothing more that they can really do to stop the cancer.

We did, the second time around, try and give him vitamins. But as time went on it got harder for him to swallow so many vitamins that we discontinued the vitamins. As Jordan's mother I had to make sure that he would be okay spiritually, because if he wasn't okay, I would not have been able to survive his loss. So I turned to my very good girlfriends, Donna and her partner Nike who live in Georgia, and asked for their help in making sure that Jordan would be okay. During this process both Jordan and I made several trips to Georgia to seek out alternative spiritual methods.

First of all, Jordan was able to talk with his Auntie Donna, and share his wishes and hopes for me because he was ready to transition into his next phase of being. This meaning he had accepted the fact that his time was getting nearer, however he was very concerned about me and wanted me to move past being angry with his dad. Second, he asked to go see Dr. Suzan Rossi, a chiropractor and multidimensional healer, who was able to help ease his pain somewhat by Divine Intervention healing. Third, he asked to go into a native Lakota sweat lodge for healing, and lastly he asked to do a fire walk seminar which included bending rebar with his throat, breaking an arrow with his throat, walking on broken glass, and the actual fire walk itself. Jordan was also able to be Gathered, a process which aligns your chakras spiritually with the Divine and Angelic Forces. He also received attunements, in which the chakras are opened and tuned with specialized Angelic and Kabbalic tuning forks. All of the above methods had allowed Jordan to get closer to spirit as he saw fit, and also made his pain more bearable. It had even given him the desire to eat solid foods, when he couldn't keep any food substance down.

Jordan and his family faced an awful, insidious disease. He very much needed conventional medical care and interventions; but also his use of complementary therapies did help him in unexpected ways.

Jordan’s use of complementary and alternative therapies, in the way of biologics, began in hopes to minimize physical symptoms of his disease and medical treatments. As time passed, his use of therapies expanded to incorporate bioenergetics therapies to strengthen him spiritually. Jordan’s mother says, “it's funny but I never really knew how much strength and determination he had, it was something we never really talked about. I guess I was too busy trying to keep it all together and afraid to hear otherwise. . . . we were both working with each other’s strengths in dealing and trying to be strong for each other.” Jordan’s essay [see the next article in this issue] confirms that these therapies not only strengthened his spirit and bonded the family, but helped prepare him for next phase of his life.

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Donna Daniels facilitates the alternative therapies that Jordan utilized and is happy to answer questions; e-mail her and reference in the subject line “Jordan.” Her email address is: heohukealo@aol.com
SELF-DISCOVERY

By Jordan Ray

Throughout life, I have discovered many interesting qualities about myself, which have all influenced my growth from a small child into a young man. In the last few months, I have begun to appreciate the value in life’s most simple pleasures, and most importantly, life itself.

So often, I get caught up with the day to day hassles and frustrations the world throws my way, failing to stop and appreciate the small things that bring me joy. I pretend as if I have the ability to control my next breath, running away from the fact that the power of life and death is beyond my control.

In November, I was diagnosed with lung cancer. Slowly but surely, my cancer cells metastasized and spread quickly throughout my entire body, causing me to be a homebound student, a regular hospital patient, and what the doctors label as a “terminally ill cancer patient.” I never know whether or not I will be able to give my mom a kiss goodnight, or even tell my siblings how much I truly care about them each day. As you can see, I'm not exactly your average teenager. When you are confronted with these situations as a young man who has not even had the opportunity to explore life beyond high school, it is enough to drive a person into a state of depression. I am unlike most students who are able to go to school each day, hang out with their friends, drive around and go shopping or to parties. Instead, I struggle doing basic everyday functions that many of us have the ability to do very quickly, but take for granted. In my situation, I have discovered a great inner strength within me that I never knew existed. As far along as my cancer is, I will not allow it to defeat me. I will fight strong and hard, enjoying the beauty in each day. My cancer is like a consuming fire. It swept through my body, destroying what it could, but because I have hope and strength, I will not allow it to burn a hole in my spirit, making me grow angry. No one seems to understand how I can manage my disease so well, or how I can keep a smile on my face, but it's quite simple. I believe that everything that was thrown my way was meant to slow me down, and help me to appreciate the things in life I was taking for granted. This experience has been a period of restoration for me. While many may see it as the complete opposite, my mind and spirit have been enlightened. And I have more joy now than I had before my diagnosis.

During my journey of self-discovery, I am growing more and more each day. With faith as my foundation, and my family and friends by my side offering their love and support, I will remain strong no matter how bad things ever get. Since I now understand the source of my joy, I appreciate life all the more.

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COMPLEMENTARY THERAPIES:
A JOURNEY FROM PROFESSIONAL TO PERSONAL

By Lisa Buell
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Energy work is airy, fairy, mumbo jumbo, evoking smells of patchouli oil, and hippies reading each others' auras. Polarity Therapy was part of my massage school certification program. I begged the administration to accept course work in acupressure or sports massage instead of energy work, something less “woo woo.” Physical education was my background; in college, I spent hours in the anatomy lab working on cadavers, fascinated with the inner workings of the human body. The energy I was familiar with came from the Krebs Cycle, not crystals or chakras. My request denied, I gathered my black and white self and headed for Polarity Therapy class convinced it was all a big waste of time and money. What I didn’t know was how much energy work would influence my career or how profoundly it would affect my family when my own child became seriously ill.

Over the years, I have woven energy work into my massage practice as a complement to the physical techniques of: Swedish, Deep Tissue, Acupressure and Sports Massage. Frequently, my clients go into a trance like state, their breathing deepens as their bodies twitch, muscles melting into the table. My clients ask what I do to make them feel so relaxed. I tell them about the energy systems in the body, how energy work can open up blocked pathways. I don't make any claims, often saying, “We don't have to believe for it to work.” After seventeen years in the massage business, I have seen and felt the effects of what massage work, especially energy work can do for people.

Touch was particularly painful to one of my clients battling cancer. The chemotherapy made him feel like his skin was on fire. I had no other choice than to use energy work for the entire session. My client slept for two hours on my table after I finished. Wanting him to sleep but afraid he might fall, I put pillows on one side of the table and rested on the floor on the other side. I guess I thought I might be able to catch him if he fell. My client was so thankful for the rest; he said he felt like he only dozed for a few minutes. We worked together for three years and in that time he told me how much the massage was helping him feel integrated in his body, energized, less stressed, and more relaxed, while also increasing his ability to focus.

Did my work “cure” him? No. My client died three years after his bleak prognosis. But during his battle with cancer he was able to play in his soccer league, hike, bike, even coach his daughter’s track team. Complementary therapies gave him a quality of life that even healthy people would envy. Since then, clients faced with challenging issues such as AIDS, cancer, paralysis, muscular dystrophy, autism, and sexual abuse have poured into my office. I don't think I can cure them, what I do is provide a safe, loving space where healing can happen.

Complementary therapies weren’t the first line of defense when our five-and-a-half-month-old daughter was diagnosed with cancer. We opted for what was proven, putting Madison's life in the hands of exceptional pediatric oncologists, surgeons, radiologists, nurses, and anesthesiologists. If untreated, the cancer was sure to kill her, but so could the treatment. We threw every recommended treatment at the cancer. Her quality of life was the point off which we navigated the maze of medicine, hashing out benefits vs. burden. We sought complementary therapies in an effort to support our daughter's system throughout the rigors of treatment.
Lavender wafted through our daughter’s hospital room as we desperately tried to keep her nausea under control when the Zofran wasn’t cutting it. Not only did it help Madison, it also relieved our anxiety. We wrapped ourselves in colors that were thought to heal, and filled her room with teddy bears, balloons, blankets, and clothing all in various hues of orange. We heard of a woman who “energetically operated” on the sick; removing tumors, healing ulcers. After talking with several of her clients, I held Madison in my lap, while this woman with hands of warm bread put them on my daughter.

The healer offered us hope without cuts, burns, or poisons. Madison drained both my breasts and slept for hours after her first session. We saw this healer several times before the spell was broken, finding her with a cigarette in one hand and a sixty-four ounce Coke in the other.

We dusted ourselves off and found a bright and shiny new “healer.” This one did Reiki, training both my brother and me in the tradition. Before working with this healer, Madison was admitted into the hospital with fever every time her counts were low; after receiving regular Reiki sessions, I think she only got a fever once out of her last seven chemo treatments. The healer told us she could use the Reiki energy remotely, that touch wasn’t necessary for the energy to work. We laughed out loud when she told us she had worked on Maddy remotely, but sure enough those were the times Madison slept soundly or had a marked increase in appetite, reminding me yet again that we don’t have to believe for it to work.

The surgery was set to remove Madison’s tumor. The hospital allowed the healer to be in the operating room. We hedged our bets taping a rose quartz to the bottom of Maddy’s foot before handing our groggy child over to the anesthesiologist. Meanwhile, my brother organized family and friends in a drum ceremony on the rooftop garden of the hospital. The surgeon was astonished to find no visible signs of the tumor in Maddy’s pelvis.

During our daughter’s all too brief life, she received multiple therapies: massage, sound, Chiquong, aroma, and water therapy. We simultaneously charged ahead with traditional treatments even though each chemotherapy session assaulted our psyche as much as it did Maddy’s cancer cells. We violated our daughter with the shots that pierced her skin, tubes that were shoved down her throat, and a port that hung out of her chest robbing her of her innocence and us of our peace of mind. Complementary therapies empowered us through the tensions of treatment.

After Maddy relapsed we were able to get a good sample of the tumor; it turned out that Maddy’s type of cancer usually didn’t respond to treatment, typically killing its victims within a few short months. We were lucky enough to have Maddy for two and a half years. Did complementary therapies give her that extra time? I don’t know, but balancing eastern and western medicine enabled us to fully appreciate and participate in the life we had with our child.

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CAM: DIETARY SUPPLEMENTS

By Constance (Connie) Bergh, MSH, RN

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The National Center for Complementary and Alternative Medicine (NCCAM) identifies therapies outside the area of western traditional medicine in the United States as Complementary and Alternative Medicine (CAM). "Complementary" is used to describe therapies that are being used in conjunction with traditional medical practices and "alternative" as therapies used in the place of traditional practices. The terms "holistic" or "integrative" medicine are being used more frequently in place of "CAM" (NCCAM, 2009). Holistic medicine focuses on patient-centered care and includes biological, spiritual, social, and environmental components while integrative medicine is relationship-based care that includes contemporary medical practices and complementary therapies (NCCAM, 2009).

Kemper’s (2002) model of holistic care describes common and not so common treatments that patients and families may seek out. The four elements of this model include biochemical, lifestyle, biomechanical, and bioenergetic. Biochemical treatments include medications, dietary supplements, vitamins, minerals, and herbal remedies. Lifestyle therapies include nutrition, exercise/rest, environmental (heat, ice, music, vibration, and light therapies), and mind-body therapies (hypnosis, biofeedback, counseling). Biomechanical therapies include massage and bodywork, chiropractic and osteopathic adjustments, and surgery. Bioenergetic therapies include acupuncture, radiation therapy, magnets, Reiki, healing touch, qi gong, therapeutic touch, prayer, and homeopathy (Kemper, Vohra, Walls, & Task Force on Complementary and Alternative Medicine the Provisional Section on Complementary, Holistic, and Integrative Medicine, 2008).

The reasons families choose CAM therapies are varied. Ethnicity and culture play a role in choosing CAM (Jankovic et al., 2004). Some families feel that CAM is more in line with their own values and beliefs and provides more personal attention (Jones, 2000; Palinkas, 2000). Families report discontent of traditional medicine and fear of adverse drug effects from traditional treatments. Families also seek CAM after other parents suggest or report success of particular therapies. For children in palliative and hospice care families often turn to CAM as traditional treatment options diminish and more symptoms arise from disease processes. Families of children that have poor prognoses may seek out more unorthodox treatments to assure that they have done all possible to heal their child or find a cure.

CAM, integrative, and holistic medicines and treatments are becoming more mainstream and are increasingly used by adults, adolescents, and children (Loman, 2003). A National Health Interview Survey in 2007 (NCCAM, 2009) revealed that almost 12 percent of all children used some form of CAM within the last 12 months. The frequency of use among children and especially children with chronic or terminal conditions is likely much higher (Loman 2003, Pitetti 2001). Other indications of use showed that children whose parents used CAM were more likely to use CAM. Children with multiple disorders, children 12-17 years of age, and those with families who delayed or did not use traditional medicine were also more likely to use CAM. The 10 most common used therapies in children are natural products, chiropractic, deep breathing, yoga, homeopathy, traditional healers, massage, meditation/prayer, diet based, and progressive relaxation (NCCAM, 2009).

Biologically based therapies are the most used CAM therapy by children. These includes botanicals, animal-derived extracts, vitamins and minerals, fatty acids, amino acids, proteins, prebiotics and probiotics, whole diets, and functional foods. A dietary supplement is a product intended to supplement the diet, contains one or more dietary ingredients (including vitamins, minerals, herbs or other botanicals, amino acids, and certain other substances), to be taken by mouth (tablet, capsule, powder, softgel,
gelcap, liquid) and is labeled as being a dietary supplement. Of the biologically based therapies vitamins and minerals are by far the most commonly used, with up to 41% reported use in the pediatric population (NCCAM, 2009).

Pediatricians reported that 87% of families had asked about CAM options, the majority asking about dietary supplements (Kemper & O’Connor, 2004). Though vitamins and minerals are prescribed as part of disease management, many children were also being given non-prescribed supplements by their parents. The use of dietary supplements is shown to be common in chronically and critically ill children. In one study two-thirds of the parents reported use of supplements with higher reported incidence in the child who had a poor diagnosis or minimal treatment options (Ball, Kertesz, & Moyer-Mileur 2005). In the chronically ill child, 40% of parents stated use of supplements along with prescribed or over the counter medications, most children were taking one or two supplements but some took as many as nine supplements (Pitetti, Singh, Hornyak, Garcia, & Herr 2001). Taking an excess of dietary supplements may lead to toxicity, harmful and serious side effects, possibly even death. There is a potential for adverse drug reactions particularly in the case of herb-drug incident. Dietary supplements have the potential to be just as active as prescribed medications and may alter, increase, or depress the action of prescribed medications (De Smet, 1996; Matthews, 1999).

Some CAM has been scrutinized by medical trials and proven effective; however many therapies remain subjective causing uncertainty for the healthcare provider when working a plan of care with families. For children with disabilities and chronic illnesses there are less established guidelines (Committee on Children with Disabilities, 2001). Because the US Food and Drug Administration (FDA) does not regulate dietary supplements closely there is concern for safety and efficacy. The FDA does monitor safety once the supplement is available to the consumer, but many if not most biologics are non-regulated and do not have to prove safety or efficacy (FDA, 2009) before entering the market. Label claims and package inserts are monitored by the FDA and advertising of supplements is monitored by the Federal Trade Commission. Manufacturers do not thoroughly test safety, purity, potency, or quality (Palmer et al., 2003). Dietary supplements may claim the ability to treat a deficiency, and support health or a body function only if there is research to back up the claim (FDA, 2009).

In a study by Lanski (2003) parents stated that they believed dietary supplements to be natural and safer than traditional medicine. In some cases parents were unaware they were giving their children supplements that are considered dangerous. Herbal supplements may pose additional concerns. An herb, also called a “botanical”, is a plant or plant part that is used for its flavor, scent, and/or therapeutic properties. Herbal supplements may include single herb or mixtures of herbs. There may be inconsistencies or misidentification in the plant species and amount of active ingredient in the supplement so the actual strength may be higher or lower than labeled (De Smet, 1996). Herbs and other botanicals can be very complex in structure and the active ingredients may not be precisely known giving way to added variations between supplements that are labeled as equivalent. The supplement itself may contain contaminants or the manufacturing process may contaminate the supplement with pesticides, metals, other herbs, and even prescription medications (FDA, 2009).

For providers practicing in JCHAO facilities there is lack of established protocols or policies addressing the use of supplements while at an inpatient facility. There should be standardized inquiry to supplement use in patients, ways of documenting use and adverse reactions, and having knowledgeable resources available to staff when questions or concerns arise (Kemper et al., 2001). JCHAO defines a medication as “any prescription medication, sample medication, herbal remedies, vitamins, nutraceuticals, over the counter drugs, vaccines, diagnostic and contrast agents, used on or administered to persons to diagnose, treat, or prevent disease or other abnormal conditions” (JCAHO, 2004). Facilities should recognize the liability of use of supplements by patients and have waivers signed to reduce that liability (Krull, 2004). The American Society of Health-System Pharmacists (ASHP) makes recommendations for facilities that allow parents to use dietary supplements with their children that have not been prescribed as part of an
established medical regimen. The ASHP recommends that an order (prescription) should be written and present in the medical record and the pharmacist should assess and confirm the order.

Very few parents discuss supplement use with the child’s health care provider (Ball, 2005). Most parents receive information about dietary supplements from books, magazines, and stores; and many times are not being educated about dietary supplements from healthcare providers but from family, friends, and advertisements (Lanski, 2003). Parents may have trouble interpreting information and have been found to have difficulty understanding dietary supplement labels.

Patients and parents do not tell about the use of CAM because they feel the provider is not knowledgeable or interested in CAM therapies (Sibinga, Ottolini, Duggan, & Wilson, 2004). Parents have indicated that they felt disclosure of use was not important or the provider never asked about use of CAM therapies. Parents also felt that they would be ostracized if they told the provider they were considering or using CAM. Care should be taken that the practitioner not feel challenged by parents who wish to try new therapies and offer to help monitor results if they choose to try a therapy (Committee on Children with Disabilities, 2001).

When considering a CAM with a family, providers should advise parents to be very cautious of some therapies. Red flags of non-conventional therapies: claims it is “secret” and only provided by certain people, statements that the therapy can cure any kind of cancer or disorder, an advertiser who states the treatment is persecuted by conventional medicine or attacks the medical community, and when the promoter requires a large amount of money up front (Jankovic et al., 2004). Therapies that are found to be harmful should always be firmly discouraged.

The healthcare practitioner should be prepared and well-informed as CAM continues to grow in use and parents seek guidance. Practitioners should be educated and familiar with types of CAM especially those treatments specific to a certain specialty or area of practice and able discuss and provide information to parents about the CAM they are seeking to assure their knowledge is accurate (Jankovic et al., 2004). Parents of children with chronic disorders reported they do want their healthcare providers to be able to advise them in CAM therapies (Liptak, 2006). For families the use of CAM allows a sense of control over the illness and an opportunity to improve their child's quality of life (Committee on Children with Disabilities, 2001) if not its duration. Scientific data concerning CAM are scarce, especially in the area of dietary supplements. The subjectivity and lack of quantification contribute to difficulty in performing studies. Unfortunately there is no agenda from NCCAM for studies concerned with palliative and hospice care and even less chance for those studies to focus on children.

As practitioners we may understand linguistics of current and emerging practices; however the patients and families in palliative and hospice care programs are more likely to understand more established terms of complementary and alternative. When discussing CAM therapies with patients and families it is best to be very specific in wording to discover the types of therapies that they may be considering or using; use specific terms such as "vitamins," "minerals," "herbals," "yoga," etc. Ask patients and families what type of therapies they are currently using, have used in the past, or are considering. Many times specific words or phrases may encourage or bring to mind a therapy that the family has used or thought about using. Other questions which might lead to disclosure include asking how specific symptoms are being managed (Kemper, 2008).

Parents of children with disabilities and chronic illnesses have further reasons for turning to CAM. Parents of children with complex disorders are especially receptive to the individual attention many CAM therapies offer. The complicated treatment plans and medical devices, difficulty in symptom management, and the uncertainty of cure are common motives for the use of CAM in children under palliative and hospice care. The seemingly innocuous status of vitamins, minerals, and herbs makes it easy for families to try these dietary supplements without consulting healthcare providers.
Palliative and hospice care evolved alongside of CAM to assist conventional medicine in symptom management and attaining a better quality of life (Horowitz, 2009). To successfully assist families in palliative and hospice care it is necessary to encourage discussion and not be negative about CAM. Forcing patients and families to choose either/or may leave them dispirited. Just as important is the ability to recognize those therapies that may be harmful or therapies that lead families to false hope; taking away energy that may be needed for palliative treatments and preparing for the last days of life.

### References


ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).


Other resources and links

National Center for Complementary and Alternative Medicine  http://nccam.nih.gov/
List serve for NIH NCCAM https://list.nih.gov/cgi-bin/wa?SUBED1=nccam_update-I&A=1
Memorial Slone-Kettering, non biased information on botanicals and descriptions of some CAM therapies http://www.msckc.org/mskcc/html/11570.cfm
Not specific to CAM but related to end-of-life and not yet approved drugs http://fora.tv/2007/09/25/Access_to_Unproven_Therapies_A_Depbate
Dietary supplements alerts and warnings http://www.fda.gov/Food/DietarySupplements/alerts/default.htm
Natural Medicines Comprehensive Database www.naturaldatabase.com
Promoting Health Through Creativity: Supporting the Emotional Needs of Hospitalized Children and Their Siblings Through Therapeutic Activity Books

By Steffanie Lorig
Founder/Director of Art with Heart
http://artwithheart.org

“When I’m in pain, I go through the book and it gets my mind off the pain and helps me relax and have fun. I put the pictures around my room to remind me that when I am sad, I can look at them and they take my mind off things. This is a good thing for other kids because it’s creative and gets you thinking and feeling better.” ~ 11 Yr. Old Surgical Patient, Children’s Hospital, Seattle

Complementary therapies play an important role in holistically caring for and supporting the families of children with special health care needs.

One therapeutic intervention that is receiving more and more attention is the use of creativity to heal, distract, and engage hospitalized children and their siblings. Activities based in creativity and imagination connect them with an emotionally healing process that helps them access and explore pent-up emotions, decrease anxiety, increase communication, and restore or improve mental and emotional health. Art also helps them physically by improving their eye-hand coordination, increasing muscle control, exercising fine motor skills, and stimulating neurological pathways.

Despite the importance of the psychological and physical benefits of therapeutic art, it’s just plain fun! In the midst of complicated medical procedures and beeping machines, children find comfort in the trappings of youth: crayons, markers, paper, paint, and activity books.

As a child with asthma, I frequently found myself hospitalized and fearing for my life. But like many difficult things in life, there was a silver lining. The fear and anxiety that I experienced helped to lay the groundwork for my passion for children and healing.

When I founded nonprofit organization Art with Heart in 1996, I was motivated to help make a difference with children – hospitalized children in particular. Our mission is to improve the lives of high-risk youth through therapeutic tools that promote emotional health and well-being. We do this best through our activity books, which are built upon research of effective, therapeutic, and arts-based interventions. We draw together the knowledge from the experiences, analysis, and recommendations of mental health professionals, Child Life Specialists, art therapists, and others who work with children. We then combine these resources with our unique relationship with children’s book illustrators to bring the pages to life – changing what could be perceived as “broccoli” (e.g., good for them) into something special they are thrilled to receive and work on. It’s a unique, eclectic, and deliberate combination of writing, art, and cognitive behavioral therapies designed to enhance existing service delivery to youth in a variety of settings.

Therapeutic Activity Book for Hospitalized Children: Our first book was inspired by Hallie, a little girl with neuroblastoma. She had been diagnosed when she was 12 months old. I met her when she was five and still fighting for her life. Her plight, along with my own personal hospital
experiences, motivated me to figure out a way that Art with Heart could help. Through years of research and both local and national collaborations, *Oodles of Doodles* was born. Hidden behind the colorful imagery are therapeutic benefits that give the children a much-needed sense of control and a safe place to express their fears and worries.

In 2005, Art with Heart surveyed healthcare professionals across 12 states working primarily with pediatric oncology and cardiology patients. 84% reported “Oodles helps me communicate with my patients” and 58% reported, “Oodles helped to increase patient satisfaction.”

“Oodles” has been endorsed by the Lance Armstrong Foundation, Make-A-Wish Foundation, The Society for the Arts in Healthcare, and Starlight Children’s Foundation/Canada, and is integrated into care by an estimated 500 hospitals across North America and Canada.

**THERAPEUTIC SIBLING BOOK:**
*Magnificent Marvelous Me* was inspired by, Katie, who grew up in the shadow of Hallie’s illness. As *Oodles* made its way in the world, we began to hear stories from siblings like Katie of how their overburdened parents focused on the sick child, leaving them alone to deal with feelings of guilt, powerlessness, loneliness, anxiety, depression, anger, and jealousy. We found studies that showed that these siblings were at higher risk than others to experience psychological difficulties, including PTSD.

Jennifer was 10 when her two-year old brother was diagnosed with a malignant brain tumor. She told us, “I felt like I disappeared during that time and for a long time after. My family was so focused on him and his illness that there was no time left for me…” The negative feelings can ultimately contribute to behavioral and emotionally-rooted problems extending into adulthood – these children have difficulty expressing their own needs, are unable to create clear boundaries, and often feel they do not deserve affection or caring.

Jean grew up with a sister with Williams Syndrome and shared, “As a child I sensed, wrongly, but understandably, that if I could just lighten my parents’ load a bit, I might win more of their love, approval, and time. So I began a pattern of denying my own needs in favor of helping other people with theirs, which took many years to understand and change.”

And so, based on feedback, Art with Heart began researching to see how we might be able to address the unmet needs of siblings and through a collaboration with 16 mental health advisors from Providence Hospice, Seattle Children’s, Inova Fairfax Hospital for Children, The Dougy Center for Grieving Children & Families, Starlight Children’s Foundation/Washington, and The Healing Center, among others.

Like *Oodles*, the book is filled with engaging drawing and coloring activities, with age-appropriate short questions and
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answers. Its title reflects the deep-seated need for the child to matter, and to find their own voice in the family. The goals and key benefits of Magnificent Marvelous Me! are to:

- support positive relationships and increase communication in the family structure;
- promote emotional development and foster emotional adjustment skills; and
- introduce creative coping and stress-reduction strategies.

**THERAPY FOR TEENS/TWEENS: Chill & Spill** is a guided, therapeutic journal that was inspired by the tragic events of 9/11. We wanted to be able to reach out to adolescents who were dealing with emotional trauma and provide youth with a way to express themselves in a creative (yet structured), comfortable (yet challenging) manner. The 20 activities are based on key elements of behavioral, narrative, and art therapies that have been shown to be effective with youth. Chill & Spill provides a way for them to actively engage in the activities either in their own time or with adult guidance, allowing reflection on personal growth when they review past activities.

Key benefits include:

- foster meaningful connections with caregivers;
- increase self-awareness and self-expression;
- enhance youth’s ability to manage emotions and stress; and
- make healthy, positive choices.

Art with Heart recently concluded a year-long evaluation study of the effects of Chill & Spill on youth dealing with everything from typical teen issues to sexual and physical abuse. The results will be made available on our website and by request.

Art with Heart offers trainings throughout the year where we share how to use Art with Heart’s books to support your work and gain an understanding of how to encourage creativity, even with children with limited physical capacity. More information can be found at artwithheart.org/events.

**FURTHER INFORMATION**

- Art with Heart: [http://artwithheart.org](http://artwithheart.org)
- American Art Therapy Association: [http://www.arttherapy.org](http://www.arttherapy.org)
- The Society of Arts in Healthcare: [http://thesah.org](http://thesah.org)
- Arts in Health & Care: [http://arttherapy.wordpress.com](http://arttherapy.wordpress.com)
REFERENCES


INSIDE THE KIDS PATH GARDEN:
HEALING GARDENS OFFER SUPPORT FOR CHILDREN WHO ARE GRIEVING

By Sally Cobb
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HOSPICE AND PALLIATIVE CARE OF GREENSBORO (HPCG), Greensboro, North Carolina: When a child who is seriously ill or grieving is driven up to the Kids Path (KP) facility to begin the process of healing, it is our wish that before they enter the door, they are greeted by a landscape that embraces them, inviting them into a safe and caring place. We strive to symbolize a stable, constant reminder that beauty and order are available in the midst of confusion, pain, and other unfamiliar feelings.

As the Horticultural Therapist on staff, achieving healing gardens that envelop our man-made buildings is a primary goal. Simply viewing nature’s splendor may allow us to begin to relax and unwind. Through nature, feelings of comfort may be experienced amid the feelings of grief.

How is this achieved in the Kids Path garden? Plants that have gentle smells, “touch me” textures, and deep and vibrant colors awaken the senses and draw attention to themselves, begging for interaction. As children become engaged with nature’s non threatening miracles, smiles emerge, relaxation creeps in, and conversational opportunities may emerge.

Before purchasing garden elements, consultation with the Kids Path team is crucial since they are using the gardens therapeutically. With a limited amount of space, each element and plant is chosen with this in mind. For

Fragrant spearmint with label made by a
Girl Scout troop.
example. Alphabet Gardens are common in children’s settings with a bold letter being “planted” beside a plant beginning with that same letter. When asked if they would find an Alphabet Garden helpful, the Kids Path team discussed it among themselves. A therapeutic idea emerged. Instead of scattering the letters randomly, they would be used to spell “Feelings.” When the children come into the “Feelings” garden area, the counselor may open up an avenue for conversation around the letters. “I suppose you are feeling a certain way today. Do you see a letter that begins that feeling?”

A whispering bench along the garden path, made possible with grant money, also invites sharing and validates that “some feelings are too painful to say out loud.”

Raised beds provide a space where a small group can gather and symbolically unite the grief process to the plant cycles. With groups meeting throughout the year, children plant bare bulbs in the late fall. Months later, after enduring the necessary process of waiting and developing, glorious tulips and daffodils pop through the soil proclaiming, “Look how far I’ve come since my bare bulb days!”

Such possibilities exist for allowing a garden to help facilitate the process of grief!

In our Kids Path Garden, there is a yellow rose bush. It was tenderly planted by siblings who had shared with their KP counselor that their mother had loved roses as well as the color yellow. After planting, they designed and painted a ceramic tag dedicated to her. Painted stones and river rock are left throughout the garden by other children who have chosen to share their feelings and memories of their loved one. The peaceful garden accepts all offerings and shares with us the reality of the changing of the seasons.
Today it is widely recognized and thoroughly documented that music can have a positive and motivating effect in connection with many forms of therapy and treatment. The fact that music is an expressive "language" that speaks directly to our emotions and affects our innermost feelings is a well known truth, recognized intuitively by us human beings from the dawn of time. But it is only within recent decades that the use of music as a complementary tool in treatment situations has been accepted and taken seriously by the professional healthcare establishment, because there is now significant scientific evidence that music can have a measurable positive effect.

"Music as medicine" – but which music?
The PubMed database contains thousands of articles describing various research projects with music in many different care and treatment situations. But in most studies described, the music is rather haphazardly chosen and selected without much consideration of volume, dynamic changes, tempo, and psychological impact on the patients. Using already existing music is of course an obvious and tempting solution, but it is important to remember that the term "music" represents so many different styles and genres that it is simply too superficial just to claim that "music is good for treatment" without specifying exactly which specific elements in music is suitable and which is not.

In this case the music itself is the "medicine" and should be taken as such, indeed just as seriously as all other kinds of medicine with of course consideration to which ingredients the medicine contains.

In recognition of this, and acknowledging a general need to improve the sound environment in hospitals, a new project was initiated in Copenhagen, Denmark in 1998 – a project founded on the known fact that music can have a significant positive effect in many treatment situations. But also a project with the aim of "going a step further" and to simultaneously create and scientifically document a new kind of music/sound environment, created especially for treatment purposes. This new music program was tested on patients using common and approved research procedures, and the patient’s feedback and reactions also served as a guideline in the ongoing creative process of developing the specially designed music.

The interdisciplinary research project Musica Humana
The “Musica Humana" project was initiated by Professor, MD Lars Heslet and the composer Niels Eje, together with musician, producer, and project coordinator Inge Mulvad Eje – and the project received substantial economic support from the humanitarian foundation "Egmont".

Apart from the promoters this interdisciplinary group consisted of doctors, nurses, and therapists from several university hospitals in Denmark, Sweden, and Norway, all who contributed actively in carrying out research projects with the new music program, which subsequently became named "MusiCure" by the composer.

The research
Research and implementation of the music in hospital wards began at the Danish National University Hospital’s ICU 4131 in September 1998. During this pilot project the general sound environment in the ICU was critically reviewed and analyzed in an interdisciplinary perspective, where professional musicians in collaboration with the doctors and nurses investigated how it could be improved. It was observed that the staff simply had grown accustomed to the sounds of alarms, respirators, and other machinery...
contributing to a stressing and frightening sound environment in the ward, but nevertheless wanted to test the suggestions from the composer and try out a combined music and nature sound environment.

The program was tested over a period of approximately 10 months and it became obvious for both staff and patients that the music seemed to "overrule" the negative and stressing elements in the existing sound environment and created a new soothing atmosphere. In the test period the researchers obtained much valuable experience by collecting feedback directly from patients, staff, and relatives. This information was also very helpful for the composer to further refine the music and pinpoint exactly which elements in the compositions that had the optimal effect on the patients.

From 1999 a number of controlled clinical trials were initiated at University hospitals in Denmark, Norway, and Sweden. The studies were at first focused on a limited selection of patient groups, concentrating mainly on recovery and cardiac patients, and subsequently also psychiatric patients.

Three of these studies were eventually published as articles in the International journals Intensive and Critical Care Nursing and European Journal of Cardiovascular Nursing.

What the research showed was a significant improvement of patient well-being, less stress, pain and anxiety in the music-groups (compared to the non-music control groups) and perhaps most important and positive: a reduced use of medication among the patients who listened to music.

Examples:
A widely-reported pilot study at the psychiatric ward at Horsens Hospital, Denmark, demonstrated a positive effect on 87% of patients suffering from anxiety, and showed also a significant reduction in the use of PN medicine and sleeping medication in patients diagnosed with depression, psychosis, schizophrenia, borderline, manic-depression, and PTSD. The study is published at the Musica Humana web site www.musicahumana.org and has set a new standard for use of specially designed music in the Scandinavian psychiatric wards.

A multicentre study in five post anaesthesia care units (PACUs) at three Danish University hospitals was performed to investigate patient and staff opinion of a specially designed music environment. The study included 325 patients and 91 staff members and showed a 83% positive response rate to the music among the patients and a similar rate of satisfaction from the staff; however the study also revealed that staff opinion correlates very much to other factors and general working conditions (stress, management, environment) in the wards.

Within recent years new studies at University hospitals in Örebro and Göteborg, Sweden, have shown remarkable results in relation to the decrease and increase in hormone levels, and rates of medication, when listening to specially designed music.

Research results published in 2008 in the American journal Heart & Lung shows that treatment with specially designed music during bed rest after cardiac surgery (bypass and heart valve) in 58 patients, could reduce levels of stress hormone cortisol in the blood in the group of patients who experienced 30 minutes of music, compared with a control group who only experienced the hospital's daily sound environment. During the 30-minute rest period after surgery there was observed a significant difference in cortisol levels in two groups: the 484th 4 mmol / L in the music group versus 618.8 mmol / L in the control group.

In a corresponding study, published 2009 in Journal of Clinical Nursing, it was shown that in the music group levels of hormone oxytocin increased significantly in contrast to the control group for which the trend over time was negative, i.e., decreasing values. Subjective relaxation levels increased significantly more and there were also significant higher levels of PaO2 in the music group compared to the control group.
A very recent study at the Queen Silvia Children’s Hospital in Göteborg, Sweden, was undertaken with the aim to test whether postoperative music listening reduces morphine consumption and influences pain, distress, and anxiety after day surgery. Numbers of participants who required analgesics, individual doses, objective pain scores (Face, Legs, Activity, Cry, Consolability [FLACC]), vital signs, and administration of anti-emetics were documented during postoperative recovery stay. Data was recorded from 80 children aged 7–16. Forty participants were randomized to music medicine (MusiCure®) and another 40 participants to a control group. There was found evidence that children in the music group received less morphine in the postoperative care unit, 1/40 compared to 9/40 in the control group. Children's individual FAS scores were reduced but no other significant differences between the two groups concerning FAS, CAS, FLACC, short STAI, and vital signs were shown. Children experienced the music as "calming and relaxing." (Article published 2009 in Paediatric Anaesthesia15 – quotes above from abstract).

In addition to the examples mentioned here, a large number of projects and studies with specially designed music have taken place, whereof many are described at the Musica Humana web site, including a controlled study with cardiac patients at Northwest medical centre in Seattle, WA, USA16 (article pending publication in 2010). Apart from the use of the specially designed "MusiCure" program in various healthcare environments, a wide spread use in institutions, hospices, schools, day-care centres, spa & wellness facilities, and even the military, is today also very common practise.

**What is specially designed music?**

“MusiCure" is a special kind of "sound-pictures" or "music/sound environment," created by the Danish composer and oboist Niels Eje, specifically for a variety of treatment and research purposes, but at the same time intended for a very broad use such as calming, relaxing, inspiring, and mentally motivating music for anyone to employ as a de-stress tool in everyday life.

One of the fundamental pillars of the MusiCure music is the idea our natural relation to the first "music" we hear in the embryonic stages: our mother's heartbeat, which lies in a constant basic rhythm throughout the creation of us as human beings. This is a slow pulse (50 to 80 bpm), a characteristic feature in all the MusiCure compositions.

The "genre-less" element is also important because the use of music for relaxation and stress relief shouldn’t be felt as a distraction or demand special attention in the situation – meaning that the listener must not associate the music with any particular genre or style, but simply experience it as a series of sound images, on the intuitive and subconscious level, and *feel* the soothing, relaxing and stimulating effect.

The music contains solo passages performed on acoustic instruments by highly educated classical artists, and unique natural sounds, which have been carefully selected and integrated into the music. MusiCure is "genreless" and "universal" in its expression, and consciously seeks to avoid associations with any of the traditional music genres or styles, in order to appeal to everyone, regardless of individual music taste, listening habits, and daily musical preferences.

Because of the comprehensive documentation behind the music, the CD series have since 2003 only been available at the pharmacies in Scandinavia, as well as online at [www.musicure.com](http://www.musicure.com)

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6. MusiCure "music as medicine" http://www.musicure.com/
9. Link to abstract: http://www.escardiocontent.org/periodicals/ejcn/article/S1474-5151(03)00121-0/abstract
12. Link to abstract: http://www.heartandlung.org/article/S0147-9563(08)00140-4/abstract
15. Link to abstract: http://www3.interscience.wiley.com/journal/122660843/abstract?CRETRY=1&SRETRY=0
LAY YOUR HANDS ON ME:
END-OF-LIFE LIGHT TOUCH THERAPY
FOR SERIOUSLY-ILL AND DYING CHILDREN

Adapted from a presentation by
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While light touch therapy goes by many names – Healing Touch, Reiki, Therapeutic Touch, Laying on Hands, and others, the end use is always the same – to make the recipient, whether it be a seriously-ill or dying child or his/her caregiver, heal and feel better. This could be physically, through pain reduction; mentally, through a sense of relaxation and well-being; or spiritually, via a spiritual connection that can’t be made on a “here and now” physical level. Light touch therapy can also be used to help facilitate communication between a patient and caregiver(s) or loved ones, when verbal communication may be difficult, if not impossible.

When recipient families of light touch therapy were queried about their understanding of and helpfulness associated with this type of therapy for their loved one, the words they used to name it were many, and included Reiki, Prayer, Soul Massage, Divine Intervention, Complete relaxation, and more…all words which may be helpful to use with families when offering the therapy to a dying child or his/her caregivers. Families also explained the therapy in a number of ways, including “Channeling, aligning of energy in the body,” “Contact with the patient’s energy field (which we all have),” and “Connecting of energy between two people, movement of energy in the sick person’s body,” among others. Many families commented on its helpfulness in terms of providing relaxation to their loved one (“I saw her become almost instantly calmed and relaxed, but because she is non verbal, I don’t know what her experience was.”) and on how it helped to reduce the patient’s pain (“The hands of the therapist move about the body and I think there’s a great energy there to relieve the pain.”). Importantly, light touch therapy does not just have to be for the dying child; caregivers can benefit from receipt of this therapy as well, so that they can care for themselves in order to care for their dying child.

All the different modalities of light touch therapy involve placing one’s hands on or over a person’s body for some period of time (i.e., 10 minutes or more). While the therapy is being done, it is believed that healing takes place because energy is flowing through the clinician’s hands into the patient. Patients often claim to feel some warmth and tingling while the therapy is being administered. Some clinicians of therapeutic touch claim that by placing their hands on or near a patient, they’re able to detect and manipulate the patient’s energy field (Bruno, 1999). Again, all are considered “energy work,” which benefits the recipient, in this case, the seriously-ill or dying child, by promoting healing and reducing pain and anxiety.

Because this is energy work, and therefore, may seem a bit “out there” for some pediatric patients and their families, how we offer light touch therapy to a patient and his/her family is very important, especially when the patient is a child. Suggesting this as a therapy requires both analytical and intuitive skills. It is
important for the clinician to know the family first and then to approach the subject gently. Broaching this with discussion with families might be helped by the following:

- Consideration of their familial faith tradition and trying to make linkages of this therapy relate to tenets of their faith
- Explaining it via the scientific theory of energy waves
- Offering relaxation as a basic benefit – “Would you like to try?”
- Demonstrating a simplistic example of how it might work (e.g., it’s like when you rub your skin or hands together to warm up when cold)
- Sometimes, however, there are no words for the experience

It is also important to remember that healing touch modalities like these are not for everyone, so we must let the patient and family guide us as to what they’re willing to accept and try, and not.

In some brief interviews with a variety of medical practitioners who have offered light touch therapies to their patients, they indicate the following words and language were helpful in getting the patient/family to consider availing themselves of the light touch therapy. These include:

- Referring to these therapies as “complementary therapies,” which seems to be a good opener for families
- Begin the dialogue with families by asking them what “complementary” things they’ve done to help their child through their illness as a lead-in to another type of complementary care, like light touch, to help comfort the child
- Offering the light touch therapy in a litany of other comfort care measures like prayer, visualizations, herbal remedies, and meditations, which helps them to place it with other alternative therapies and thus determine their comfort level with it, or not
- Inquiring of the family/patient what THEY do to relax; and if massage is mentioned, explaining how light touch therapy can be an extension of massage therapy (except they don’t have to be physically touched)
- Explaining that in therapies like this (e.g., Reiki), the recipient of the therapy draws in the amount of energy they need to return to balance and wellness.

Conversely, some medical practitioners interviewed claimed they found it difficult describe this type of therapy to patients or that when they did, it just was not clear to the patients:

- “I struggle to explain this to patients. I used it with a demented, non-verbal patient and I think I said something like 'I'm going to run my hands along your body to see if it helps you relax.'”
- “Energy work”, which some found may be too nebulous for patients to understand

When unable to explain it, some practitioners request help via consultation from other members of the inter-disciplinary team and the patient and his or her family.

To be effective, the sharing of light touch therapy needs to be done by someone trained in the modality. This might be a healthcare professional (i.e., Nurse, Chaplain, Social Workers, Physical Therapist, etc.), or it could be a caregiver or loved one. Some hospitals are offering healing touch training classes for staff and families alike. For families, some clinicians have found it offers them a sense of empowerment and facilitates their ability to be effective caregivers. Clinicians interested in offering therapeutic touch therapy to pediatric patients may want to come to the position already with this experience in case it is not offered where they work. There are also many local educators offering training of healing touch modalities at the community level.
There are a number of pediatric hospital and/or hospice-based programs which are beginning to, or have already incorporated, light touch therapies into their care of dying children and their families. Some of the specific children’s hospitals currently offering light touch therapies for their pediatric patients include: Children’s Hospital & Regional Medical Center in Seattle, Lucile Packard Children’s Hospital at Stanford, Children’s Hospital of Pittsburgh, Children's Hospital of Los Angeles, Children’s Hospital Boston, and Cincinnati Children’s Hospital Medical Center, among many others.

When a recipient family of light touch therapy was asked what was most helpful about the treatment for their loved one, they responded: “Immeasurable, loving, personal, undivided attention addressing both (her) physical and spiritual needs.” What more would one want to do for dying child in his or her final months, weeks, days. Let the touching, and importantly, the healing begin.

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Coordinator, Stepping Stones Program
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Benor, D.J. (2001). Spiritual Healing: Scientific Validation of a Healing Revolution. Pub. Vision Publications. A compilation of scientific studies (that the author has decided based on his own criteria) on various forms of spiritual healing including light touch therapy. See especially chapter four, which details the effect of light touch therapy on a variety of subjective experiences.


Myss, C. (1996). The Anatomy of Spirit. Pub. Three Rivers Press. Caroline Myss is a highly accurate medical intuitive. This book is her account of how she is able to diagnose illnesses knowing only the name and physical description of the patient, and her goal to teach each of us how to do this and how to take care of our own energy. She explores our bodies in terms of energy and achieves some interesting integration of the mystical ideas of Western and Eastern faith traditions.


**Journal and Magazine Articles:**


Engebretson, J., & Wardell, D.W. (2002). Experience of a Reiki session. *Alternative Therapies in Health and Medicine, 8*(2), 48-53. Interviewed 23 recipients of Reiki just after the treatment. “Participants described a liminal state of awareness in which sensate and symbolic phenomena were experienced in a paradoxical way, and self paradox also was seen in participants’ symbolic experiences of internal feelings, cognitive experience, and external experience of relationship to the Reiki master.” The authors conclude that: “Liminal states and paradoxical experiences that occur in ritual healing are related to the holistic nature and individual variation of the healing experience. These findings suggest that many linear models used in researching touch therapies are not complex enough to capture the experience of participants.”


Documents research into the interests of different complementary therapists in conducting scientific research.


Mackay, N., Hansen, S., & McFarlane, O. (2004). Autonomic nervous system changes during Reiki treatment; A preliminary study. *Journal of Alternative and Complementary Medicine, 10*(6), 1077-1081. Research shows significant decrease in heart rate, cardiac vagal tone, blood pressure, cardiac sensitivity to baroreflex, and breathing activity compared to placebo or control.


Tilden, V.P., Drach, L.L., & Tolle, S.W. (2004). Complementary and alternative therapy at end-of-life care in community settings. *Journal of Alternative and Complementary Medicine, 10*(5), 811-817. Authors found that complementary and alternative treatments were used by 53% of patients during their end-of-life care. Those who used such therapies were more likely to be younger, have college degrees, and have higher household incomes. The most frequent use was for symptom relief.


**Web Sites:**

- **Healing Touch International:** [http://www.healingtouch.net/](http://www.healingtouch.net/)
  Healing touch is an energy therapy developed primarily for use by nurses. The therapy aims to harmonize the energy fields around the body. Used by more than 30,000 nurses in hospitals each year. Similar in many ways to the Reiki technique. This site has summaries of research on healing touch in health care, including research on the use of healing touch in hospice settings.

- **Healing Touch Spiritual Ministry:** [http://www.htspiritualministry.com/](http://www.htspiritualministry.com/)
  A good resource for those interested in integrating modern techniques of energy healing by touch and also the ancient Christian practices of healing touch as exemplified in Jesus.

- **The International Association of Reiki Practitioners:** [http://www.iarp.org/](http://www.iarp.org/)
  Publishes a regular on-line magazine, and offers membership and liability insurance.

- **The International Center for Reiki Training:** [http://www.reiki.org/](http://www.reiki.org/)
  A very helpful site with information about training, different types of Reiki practice and planetary healing. This center publishes a very useful magazine.

  John Harvey Gray was one of Takata’s first students and is the oldest living master Reiki practitioner in the US.

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*ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).*
PET THERAPY AND PEDIATRIC PALLIATIVE CARE

By Pat A. Frasca, MA, CCLS
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One of the most challenging dogs I have ever met was George, a stray terrier mix. George had a special therapeutic relationship with a seven-year-old girl who we will call Princess. Before you read the story of their relationship and how it relates to pet therapy and palliative care, an overview of pet therapy is helpful.

The Beginnings of Pet Therapy

In the 9th century, the first therapeutic use of animals began in Belgium with a program specifically designed for people with disabilities. Fast-forwarding to the 1800s, Florence Nightingale, pioneer of nursing, believed small pets were excellent companions for the sick. Many referred to her as the pioneer of animal-companion therapy. It is documented that Freud, father of psychoanalysis, believed dogs had a "special sense" and that his dog, Jo-Fi, attended all his therapy sessions.

Boris Levinson, child psychologist, was credited with the birth of Animal-Assisted Therapy when he coined the term "pet therapy" in 1964. His work with dogs began accidentally in 1953. Levinson was in his office with his dog, Jingles, when a mother and a new patient arrived one hour early for their appointment. This seven-year old boy had been seen by other therapists who described him as disturbed and non-verbal. As Levinson spoke with the mother, Jingles approached her son. The boy immediately took the dog in his arms and began to stroke and talk to him. We don't know much about Jingles, the first official therapy dog. We do know that Levinson first met this abandoned, longhaired puppy in front of Hunter College in New York. He had a rope around his neck and was on his way to the ASPCA.

What is Pet Therapy?

Pet Therapy is a generic term used to describe animal assisted therapy (AAT) and animal assisted activities (AAA). AAT is a goal directed intervention facilitated by a health services provider. With AAA, the interactions between human and animal are mostly casual and spontaneous.

While the research evidence on pet therapy (AAT or AAA) is slim, anecdotal support is vast. Two of the physical benefits of being with and/or petting an animal are a decrease in blood pressure and a release of endorphins (chemicals that suppress the pain response).

I have participated in pet therapy as an escort or facilitator for 20 years. In my opinion, people—adults and children alike—sense the non-threatening and non-judgmental nature of therapy or visiting animals. They sense the animal's pure presence and openness. Nothing is required of them as there is no pressure to do or say anything. These very special animals seem to satisfy the need for physical contact and provide a medium for communication, which isn’t necessarily verbal.

One important goal of pediatric palliative care is to enhance a patient's quality of life from diagnosis through recovery or death. As such, the benefits of pet therapy also include all stages of physical health. A newly diagnosed oncology child, for example, often experiences the same pain, fear, anxiety and isolation as a dying child. Visiting animals serve an important function. For example, they provide children and families with a sense of normalization. Children often initiate conversation and seek answers to their questions through contact with an animal.
Pet therapy can be seen in many settings such as hospitals, skilled nursing and assisted living facilities, psychiatric units, outpatient settings, and end-of-life facilities. While dogs are the most common visitors, other animals such as rabbits and guinea pigs are chosen for this special type of work. For more information on pet therapy with two mini horses, read Claire Vesely’s article “Hippo Who?!!” in the November 2009 issue of this ChiPPS e-newsletter.

Princess and George

Princess was one of the first patients to stay at George Mark Children’s House (GMCH), a pediatric end-of-life and respite care facility. The house was not fully staffed when Princess arrived. At times, she was the only patient there. One day, Chris, one of the nursing assistants, arrived at work with a dog, claiming this dog followed him from the BART station. He and others believed the dog knew exactly where he was going and why. They named this stray dog George, and this marked the beginning of his stay at the house. By the time I met Princess and George, both had been residents at GMCH for at least two months.

Princess was at the house for end-of-life care. Her family issues were complicated. Visitors were inconsistent and sporadic, and days would pass without a single visitor.

George didn’t seem to like people but he took a shine to two nurses and Princess. If he wasn’t in his bed under the nursing station, he was on the bed with "his" Princess. George was her most frequent and attentive visitor, and she loved having him with her. Sometimes she would talk and play with him; other times they both rested quietly. George became increasingly protective of Princess and aggressive towards others, and it became difficult for others to enter her room. Animals often show signs of aggression when they are afraid or are in “protection” mode. As more people came to the house, George became more and more skittish and fearful. Clearly, this was not a good setting for him. We all knew this, but worried what Princess would do without him. A difficult decision was made.

As the Child Life Specialist at GMCH, I was asked to find a new home for George. I contacted Smiley Dog Rescue, a local agency that fosters dogs prior to adoption. Because I had adopted one of my dogs from them, I hoped they would agree to take George as a favor to me. I told the program director everything about George. Thankfully, she agreed to take him and personally foster him.

We all were painfully aware of Princess’ strong attachment to her personal therapy dog. Telling her the reasons why George could no longer live at the house was not easy, but we told her the truth. Her seven-year-old mind cognitively understood, but that did not decrease the grief she felt about losing him. The timing was not optimal. Princess had just begun to lose her ability to speak, a sign of the growing tumor in her brain.

We helped Princess with this transition as best we could. She played ball with him out on the grass and visited with him in many places inside the house. We took photos of the two of them alone and with members of our staff. We told her how much we would miss George, and that this necessary separation wasn’t anyone’s fault. The day of George’s departure was difficult for everyone, but Princess seemed to handle it better than most of us.
We did our best to model what the loss of a loved one could look like. We talked about George often. Sometimes we told funny stories about him and other times we expressed our sadness. At lunch we often offered a toast to him with our glasses. While none of us thought he would return, many of us secretly hoped his new guardian would bring him to visit Princess before she died.

The day we secretly imagined arrived. George visited Princess with his adoptive mom twice before she died. During these precious visits, George was somewhat mellow, but still only responded positively to the same two nurses, and of course, his Princess. Once again, we took many pictures of both of them. And yes, she was happy to see and be with him, but she also appeared at peace. This time it was easier for her to say good-bye.

Obviously, George did not meet the criteria for a visiting or therapy dog, and yet he was a therapy dog to one special girl named Princess.

Trevin – A Frequent GMCH Visitor

Trevin had the perfect temperament for a therapy dog. He began visiting GMCH in the fall of 2004. People often commented on his sad expression, but he wasn’t sad at all. He was a trooper who even visited in costume on special occasions. The kids and staff loved it, and Trevin never seemed to mind what he was wearing.

Carol, Trevin’s guardian and best friend says, “The highlight of our visits was when children were reluctant at first to interact with him, but ultimately became receptive and could be heard down the hall ‘Trevin is here!’ This absolutely made our day!”

Dogs, like Trevin, have special temperaments. They understand what palliative care is about. Ironically, most pet visits are actually quite ordinary. Sometimes Trevin would sit quietly at a child’s side, and other times he would be more playful in his interactions. It has been my experience that certain dogs seem to sense exactly what’s needed. Trevin was that kind of dog. Often, a silent exchange happens between a dog and a person. Many call this connection the “human-animal bond.”
Pet therapy benefits everyone. As Carol reflects, “During my journey of awareness of pet therapy and the impact it had on the patients, I came to realize that the visitations were just as therapeutic for the staff as they were for the kids.”

In summary, the social and emotional benefits of pet therapy are challenging to measure and describe but as the saying goes “seeing is believing.” While this article focuses on one specific place, pet therapy and palliative care can happen in just about any setting. Each pet visit tends to be particularly special to at least one person.

References:


3. www.deltasociety.org

What is ChiPPS and How Can I Get Involved?

By Mary Kay Tyler, RN, CNP
Co-Chair ChiPPS

What is ChiPPS?

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Since 1998 this dedicated group of professionals has been committed to making the best-known practices in pediatric palliative and hospice care more widely available to care providers and increasing the availability of state-of-the-art services to families. As an advisory group to NHPCO, ChiPPS plays a vital role in promoting the importance and advancing the work of pediatric palliative and hospice care. The work of ChiPPS began with a conclave meeting in November of 1998. This two-day meeting in Dallas, Texas, involved 30 leaders from the field who worked to identify and reach consensus about the critical issues facing pediatric palliative and hospice care, and to develop strategies necessary to address those issues. Since 1998, the accomplishments of ChiPPS have played a vital role in shaping the entire national pediatric palliative and hospice care field.

ChiPPS is composed of a Leadership Advisory Council and 3 primary workgroups: education, communications, and access. Additionally there are three ad hoc workgroups: public policy, ethics and standards. ChiPPS also strives to have representation on NHPCO committees whose work directly ties in with current priorities of ChiPPS. For example in 2010 ChiPPS has representation on the professional education, research and ethics committees.

Vision

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Through collaborative efforts, ChiPPS will promote education, advocacy, service improvement, and research.

We are currently seeking new members to participate in our active workgroups. It is through the dedication, talent and time of those working in pediatric palliative care that ChiPPS is able to continue to grow and advance the practice of pediatric palliative care. Some of our recent accomplishments are:

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- the recently published Pediatric Palliative/Hospice Care Standards, available on-line
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- quarterly publication of our electronic newsletter

Most of the work done by the workgroup members is through email and monthly conference calls. Workgroup members are asked to serve a three year term and may be elected for a second term if they desire.

If you feel the time is right for you to become involved with a dynamic group of individuals committed to the enhancement of pediatric palliative care, please contact Mary Kay Tyler, Co-Chair of the ChiPPS via email at mktyler@hospicewr.org. Mary Kay will then send you more information via email and set up a quick call to review the details. We are looking forward to an exciting year and are hoping you will join us!
Items of Interest: In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. Subjects and Contributors for Future Issues of This Newsletter. In past issues of this newsletter, we have addressed a wide range of subjects, including bereavement, sibling bereavement, self care, ill and dying teens, perinatal loss, neonatal loss, 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. (Please note that you can visit archived issues of this newsletter at www.nhpco.org/pediatrics.) 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 work with you!

2. Reader's Corner. In issue #13 of this newsletter, we inaugurated a new, occasional feature called the Reader's Corner 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 such articles following the model in issue #13. Please send all such suggestions to Christy Torkildson at torkc@sbcglobal.net.

3. Upcoming Meeting. The American Academy of Hospice and Palliative Medicine (AAHPM), in collaboration with the Hospice and Palliative Nurses Association (HPNA), will host its Annual Assembly on March 25-28, 2009, at the Austin Convention Center in Austin, Texas. Further information can be obtained from the Academy’s web site, www.aahpm.org or by calling 847-375-4712.

4. Pediatric Palliative Care at Clinical Team Conference. ChiPPS is proud to have created a pediatric intensive track that will be part of NHPCO’s 10th National Clinical Team Conference held in Denver, CO, September 24 – 26, 2009. Please check the NHPCO website for the opportunity to submit an abstract/proposal to future conferences!

5. 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.

6. **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 www.mountida.edu/ncde or contact NCDE at 617/928-4649.

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. **What is ChiPPS and How Can I Get Involved?**

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We are looking forward to an exciting year and are hoping you will join us!

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

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.nhpco.org/pediatrics for further materials and resources of interest.