



Pediatric E-Journal



NHPCO

National Hospice and Palliative
Care Organization

PEDIATRIC ADVISORY COUNCIL

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New Look & Name

Our readers will notice that there's a new look – and even a new name – to our E-Journal. At the recent NHPCO Leadership and Advocacy Conference (April 15 – 17), the organization unveiled its new branding that affects many aspects of NHPCO and its work. What has been known as the **Children's Project on Palliative/Hospice Services (ChiPPS), will now be known as NHPCO's Pediatric Advisory Council**. The ChiPPS E-Journal will now be the Pediatric E-Journal and the **look of the publication reflects NHPCO's new branding**.

We salute the legacy of ChiPPS and the many contributions made in support of pediatric palliative and hospice care from the many members who have been a part of ChiPPS over the years. This important pediatric work will continue under the Pediatric Advisory Council and the E-Journal Workgroup looks forward to contributing to the field through the availability of the free Pediatric E-Journal.

Issue Topic: Integrative and Complementary Therapies—Part One

Welcome to the 55th issue of the Pediatric E-Journal. This issue of our E-Journal explores some of the many different types of integrative and complementary therapies that can contribute to the care provided to children, adolescents, and family members as part of the overall services offered by programs of pediatric palliative or hospice care. We were pleased and a bit surprised to realize how widespread interest in these topics was as we prepared this issue. In total, we received more than 20 contributions, the largest number of articles we have ever received for a single issue. Clearly, integrative and complementary therapies are becoming of increasing importance in pediatric palliative and hospice care, and practitioners of those therapies are ever more eager to describe their roles in these types of care.

We do not wish to complain about receiving an unexpectedly large number of contributions to this subject, but it is important that many good articles not be overwhelmed or lost in a single grouping of such articles. As a result, the Pediatric E-Journal Workgroup has decided to allow two issues on this subject, of which this is the first. Issue #56 will follow with more articles on this subject in just three months.

In the past, we had occasionally split issues on a single topic area, but more recently our desire was not to proceed in this way so that we can cover a broader range of subjects in a single year in our four quarterly issues. So, the present division is a one-time response to an unexpected abundance of riches.

Even so, we appreciate that the many articles in this and our next issue can still only cover a limited number of examples of integrative or complementary therapies. It is our hope that these two issues can spark discussion of an even larger number of ways to include similar therapies in pediatric palliative and hospice care. In any event, our goal is to provide at least a beginning in discussing such matters.



This E-Journal is produced by the Pediatric E-journal Workgroup, co-chaired by Christy Torkildson and Ann Fitzsimons. Chuck Corr is Senior Editor of the Pediatric E-Journal. Archived issues of this publication are available at www.nhpc.org/pediatrics.

Comments about the activities of **NHPCO's Pediatric Advisory Council**, its E-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are currently discussing topics such as Myth Busting for a future issue in 2019. If you have any thoughts about these or other topics, contributors, or future issues, please contact Christy at ctorkildson@mail.cho.org or Ann at ann@here4U.net

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Issue #55: Integrative and Complementary Therapies—Part One

Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.

Swimming in Zone 3

p. 6

Scott Newport, Evan's father

In this article, our resident poet and essayist reflects on an invitation to speak with a special needs father whose son has an incurable condition that may lead to a shortened life. The discussion considers the example of inner-city kids who come to summer camp and are asked to go swimming in the lake for the first time. Scott compares this to “how some of the moms and dads with sick kids are asked to come down to the deep end of the lake and told to jump in feet first...**Instead of going to boy scout camp they're like refugees forced to hospital camp, because of childhood illness.**”



Parent Realities: Navigating the Use of Integrative Therapies for a Child with Medical Complexities p. 9

Dannell Shu, BFA, MWS, Levi's Mother

In this article, **Levi's mother** considers how her family navigated the chasm between the use of integrative therapies and standard Western medicine. She **writes**, "I had no idea, two weeks into motherhood, a simple question about acupuncture to an NICU physician would lead me toward becoming a Cross-Cultural Chief Puzzle Master for my son Levi... [in order to] provide him with genuine whole-person care." **Having surmounted many challenges, she concludes:** "I am most thankful for the providers, on both sides, who could **welcome and embrace the 'other'** world. In the process, all of us have grown as people and expanded our understanding of what is possible for our children with medical complexities when we welcome genuine cross-cultural collaboration."

Essential Oils: Scarlet's Story p. 13

Jennifer Wagner, **Scarlet's** mother

As her mother writes, Scarlet's "syndrome was severe from birth and the learning curve was quick with little room for error." **Not surprisingly, "When essential oils (EO's) came into our lives through a family member, we were hesitant at first to believe that the benefits of essential oils could actually help someone, especially someone as severely challenged as Scarlet. We bought a few for respiratory support to try with the mentality of 'it couldn't hurt.'" In practice,** the family found that essential oils could help Scarlet with respiratory symptom management, illness prevention, and comfort care. Which oils were used and how they worked are explained in detail.

Expressive Therapy at Akron Children's Hospital: A Creative Refuge for Healing p. 16

Elizabeth Germano, MA, MT-BC, and Emily Grabo, ATR, LPC

This article describes a robust program of music therapy, art therapy, creative writing, and many other artist-in-residence style programming opportunities that are open to patients, families, and staff through **the Expressive Therapy Center at Akron Children's Hospital**. Quotations from those who have used these services and data about its growth since 2011 confirm their value.

Concealed Voices: Music Therapy for Pediatric Patients in Hospice Care p. 20

Yelena Zatulovsky, LCAT, MA, MT-BC, CCLS, HPMT

This article describes how music can be used in pediatric palliative and hospice care. Extensive examples, references, and song themes are used to explain music therapy and to show how music can be **"used within a therapeutic relationship to address physical, emotional, cognitive, and social needs of individuals."**

Complementary and Mind-Body Practices for Symptom Management with Children and Adolescents p. 24

Susan E. Thrane, PhD, MSN, RN, CHPN

This article explores "several mind-body practices, the scientific evidence relating to each, and how they can be helpful for children and adolescents receiving hospice or palliative care." The therapies considered include those that are professionally delivered (hypnosis and acupuncture), group movement classes (yoga), and those that are self- or patient-administered (**apps for relaxation, listening to music, meditation**). **The author concludes:** "Overall, given the minimal risk and the wide variety of techniques discussed in this article, there should be something that appeals to all ages and cognitive abilities." **And she adds:** "When a child or an adult for that matter is able to relax, symptoms such as pain, anxiety, fatigue, sleep, and stress decrease."



Acupressure and Other Complementary Therapies for Symptom Management in Pediatric Palliative Care p. 29

Joan M. Fisher, MD, PhD

In this article, the author writes, **“I strive to teach multiple modalities to parents and children to serve as bridges for the children until relief is found or more effective medical therapy is forthcoming. I always stress that non-pharmacological therapy should be a parent’s first choice to treat a symptom, since these rarely cause side effects, can be done anywhere, and cost nothing once a child had developed the competency to use the tools that we (parents and team) have taught them.”** The article includes mention of breath work, self-hypnosis, and mindfulness meditation, but most space is given to detailed guidance concerning the multiple points that can be used in acupressure.

Pediatric Massage Therapy p. 34

Marcia Degelman, CMT

This article, written by an experienced massage therapist who works with both adult and pediatric patients, makes the argument that, **“Massage therapists can play a vital role in helping the nurses, the parents, and the patients dealing with pain and anxiety. As pain medicines come under scrutiny and hospitals search for alternatives, massage therapists are ready and able to help, with pain relief and relaxation.”** The article explains both the role and the benefits of massage therapy in pediatric care.

Enhancing the Flow of Life: The Pediatric Palliative Aquatic Program p. 36

Sheila Pyatt, RN

The author explains that, **“The Pediatric Palliative Aquatics Program (PPAP) is a gentle, warm water modality designed to meet the needs of children with lifespan limiting conditions. It is especially beneficial for children who are medically fragile or approaching end of life.”** She adds that, **“The program invites participation of parents and other family members while encouraging normalization of life through aquatic activities.”** In addition to an account of the theoretical foundations of the program and its consistently observed results, the article offers a striking example in poetic form of how **“the aquatic practitioner may become acutely aware she can do nothing to affect the child’s life trajectory. She can, however, profoundly affect the child’s journey during these final, sacred moments.”**

End-of-Life Doulas as an Essential Layer of Support for Children and Families p. 40

Christy Moe Marek

The role of doulas is perhaps best known at the beginning of life in supporting families in the birth of children. Here it is argued that, **“End-of-life doulas are equipped to provide continuous, independent presence to support the child experiencing illness and facing end of life, and the family as a whole....Together, an end-of-life doula walks alongside a child and his or her family, allowing for everyone’s voice to be heard, honoring each person’s unique experience, and weaving the story of each individual within the larger context of the family story. The sense of belonging this engenders reminds them that they deserve to be heard, that their experience matters, and that they are not alone.”**

Medical Marijuana in Pediatric Palliative Care p. 44

Elissa Miller, MD, FAAP, FAAHPM

To start, this article explains key terms used in discussions of medical marijuana. It then offers a chart listing **“three FDA-approved medications that have evidence backing their use: dronabinol, nabilone, and newly on the market, cannabidiol (Epidiolex).”** The article then



explains what we do and do not know about the use of medical marijuana in pediatric care and **offers the author's advice on its use.**

[Guiding Parents to Mindfulness: Low Tech in a High-Tech Environment](#) p. 48

David M Steinhorn, MD, & Jana Din, BA

“This article develops the concept that helping families find a mindful inner state may help them make the best decisions for their child.” The authors use an example of helping the family of a child with Gaucher disease and a table of dehumanizing/humanizing behaviors to show “how a low-tech means of helping families, who are open to it, allows them to move towards mindfulness without training or extensive practice.”

ADDITIONAL NOTES

The Pediatric Advisory Council is a council of the National Hospice and Palliative Care Organization. Learn more at www.nhpc.org/pediatrics.

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, Pediatric Advisory Council and its E-Journal Workgroup, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

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 Pediatrics**. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the Pediatric Web page at www.nhpc.org/pediatrics for previous issues of this E-Journal, additional materials, and other resources of interest.

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SWIMMING IN ZONE #3

Scott Newport
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“We all just stood on the dock counting to five,” Tony explained.

I met Tony last week. Dr. Ken Pituch, Director of Pediatric Palliative Care at C S Mott Children's Hospital emailed, asking if I was willing to meet a new dad.

“Scott, we had a family meeting at the hospital and when Tony asked if there was anyone he could talk to, both his son's cardiologist and I jotted down your name.”

Tony's wife probably cringed at the thought of Tony talking to a therapist, but both Dr. Pituch and the cardiologist wrote the initials ‘S N,’ on their note pads. Yea, that's me. I'm not a therapist but I'm willing to listen.

Tony is a special needs father; his beautiful son has an incurable condition that may lead to a shortened life. As Tony continued to unravel his story he seemed buckled up for the ride. He's been taking care of his child for seven years rooted in life and death experiences.

“Sometimes I feel guilty,” he mentioned while I peered out the floor to ceiling windows just outside his son's room.

“Yea,” I said. “I know what that's like.” The corner space we were occupying is often a place I sit before I go meet a new family. I pray there often.

Guilt is part of grief; it comes and goes on its own terms, I reminisced.

When he told me why he felt guilty over his son's condition, I accepted it. Beyond the divided windows in our space I could see the Ronald McDonald House across the parking lot and the sprawling campus of the University of Michigan. Winter had just arrived, and all the trees were bare. Leaves carpeted the valley of hardwoods trees in the nature center to my left.

I replied, “If it didn't happen then, a tragic event like that could have happened when you were not there.”

Guilt is happy to take prisoners, I thought. Holding us under water till we give into its grip.

I will often say to families I mentor, “I can't take away the mountains of grief, but I'm willing to go up a couple of the hills with you.”

Tony nodded and then said, “I used to be Boy Scout counselor. I did it for seven years.”

“I was the guy the Chaplain would bring the kids to who were home sick.”

“What is your favorite memory,” I asked?



“I can still recall the one week of the camp season when the kids from the inner-city would come.”

“When it was time for them to go to the lake for swimming, I knew it would be an unfamiliar experience for many of them.”

He continued with, **“There was a counselor for each camper and we would have the kids line up on the dock, near zone three. You see, there were three zones. Number one was the shallows, near the beach, the second zone was about waste high, and the third was over your head.”**

In my head, I could picture the scene Tony had painted. I was never a boy scout, but I attended summer camp too. I imagined the square, horse-shoe shaped dock creating a barrier to open water.

Tony leaned toward me and said, “We would tell the kids to jump in feet first. Swim to the opposing dock and then swim back. But just like all the previous years. The life guards all started silently counting to five.”

Then Tony explained how he would jump in, go to the bottom of the lake, and grab the kid. The camper would be flailing and kicking. When they would breach the surface, the kids would often say, **“Why did you do that, I was swimming.”**

I couldn’t help but laugh when Tony described it so well. I mean, I could just imagine the kids who had maybe never been in a lake. They may have seen it on TV or maybe a video game, but they had never experienced the real thing. Tony was so excited to share with me and that made me feel good.

I mean his sick kid and wife were just beyond our voices as we sat outside the hospital room. And here it seemed like this dad could catch his breath from all the chaos of breathing treatments, oxygen administration, and a continuum of nurses and doctors weaving in and out of his family’s life.

I don’t remember if it was exactly in that moment, but it didn’t take me long to compare our “refuge families” we have at the children’s hospital to those kids on the dock. I asked Tony about it the next time we met.

“Hey Tony, do you ever think about how some of the moms and dads with sick kids are asked to come down to the deep end of the lake and told to jump in feet first. I just loved the way you told the story. Instead of going to boy scout camp they’re like refuges forced to hospital camp, because of childhood illness.”

I think Tony has figured out I’m a bit quirky and quickly agreed with me.

Together we spoke about how parents are lost in this world and often think they are swimming. I guess, like Tony, **I’m kind of a counselor and will often count to five before I jump in and find the parents moving their arms and legs.**

I can’t wait till one day when I pull the families up I’m working with and they may say, “Why did you do that, I was doing just fine.”



I guess in most cases they already say that, just in a different way. When I pull parents up, in most **cases the family can't even catch their breath to speak. I'm not sure if this metaphor means** anything to anyone else but Tony and me, but I hope one day I can share this with other mentors or Doctors and Nurses. I just hope that when I pull them out they will be able to see our families in a way that is helpful even when they thought they were swimming, too.

Ok, maybe I should go back to the pool and work on my freestyle. I'll ask Tony if he will stand at the deep end..... Zone #3 here I come.

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PARENT REALITIES: NAVIGATING THE USE OF INTEGRATIVE THERAPIES FOR A CHILD WITH MEDICAL COMPLEXITIES

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When my son Levi was born with severe brain damage and a long list of medical complexities we took a fast dive into the depths of western medicine. It was awe-inspiring to personally interface with its capacity and limitations. Everything in the Neonatal ICU had a protocol, from how many times a syringe could be used, to number of days on a cooling blanket, to the scope of roles and responsibilities of each specialist. The protocols (science) were skillfully being navigated with the art of caring for my son and his unique collection of complexities; which at the time were in the process of being identified.

Perhaps because of a naivety on our part, two weeks into our son's NICU stay we asked about the possibility of acupuncture. To us it seemed like a simple request given my husband's Chinese culture and our desire to find the best ways to provide Levi with whole person care. The physician's surprised eyes and dampened chuckle was our first introduction into the chasm between western medicine and integrative therapies. Seven years and 20+ integrative therapy modalities later we have learned a lot about this chasm and what it takes to navigate it as a parent.

Western Medicine = Home Base

When you have a child with medical complexities you live deep within the world of Western Medicine with its culture of providers, pharmaceuticals, therapies, surgeries, equipment, supplies, insurance companies, languages, beliefs, and behaviors. Thanks to this world your **child is alive and has opportunities to thrive that aren't available in every country. It is an automatic "home base."** There is a tremendous dependency upon both current tools and continued innovations.

However, every tool has its limitations. The longer a child is alive, the more complex their **condition, the more families experience these limitations. This reality combined with a parent's** desire to seek out the best whole-person care for their child is often a key motivation for why families step outside of the home base of Western Medicine and into the world of Integrative Therapies.

As early as my son's NICU stay, we experienced the importance of having Western Medicine as our home base while also desiring an expansion of whole-person care to include Integrative Therapies. Music, acupuncture, massage, and craniosacral therapy were some of our first steps in this direction. As Levi grew, we kept a palliative-minded focus of comfort and quality of life, which to lead us farther along the paths of Integrative Therapies. The more we became skilled with the tools of Western Medicine, the more we respected each one's purpose, limitations, and our need to continually and appropriately be expanding Levi's "toolbox."

Parent = Chief Puzzle Master





Every parent of a child with medical complexities I have met talks about the challenges of supporting the aspects of their **child that are “outside the box” of what is normative within** the long list of diagnoses. What do you do when seizures persist in spite of medications? **When vision isn’t improving** in spite of traditional therapies? When an unexplained virus surfaces with evident pain and your provider says to give Tylenol and wait it out? When the silo-nature of Western **Medicine isn’t able to fully tend** to the whole-person nature of your child? When your values of care collide with a **specialist’s recommendations?**

As parents, we experience the fullness of our children’s personalities and the realities of their medical complexities. We are the only link **between our child’s medical,** therapeutic, and educational teams. With the siloed-nature of these teams (within and between) it is up to parents to navigate how individual puzzle **pieces fit together, don’t fit,** could fit, all while maintaining the big picture of whole-person care. Being the Chief Puzzle Master means we are **continually expanding our child’s toolbox, creatively**

problem solving, investigating more ways to provide quality care and sustained comfort within the context of our values. A robust toolbox is key to relieving pain, reducing suffering, and supporting meaningful quality of life.

One of the challenges parents face is getting stuck within the necessary “tasks” of medical cares for their child. Tube feedings, medications, oxygen monitoring, and keeping a clear airway were some of the ones we juggled with Levi. Focusing too tightly on these tasks hinders our own ability to understand and support our child as a whole-person. Integrative Therapies helped us **expand our understanding of Levi’s needs and definition of what it meant to “care” for him.** Tactile cueing taught us the importance of purposeful communicative touch. Massage therapy taught us the importance of relational connection while supporting stress reduction. Bach flower remedies **expanded our understanding of Levi’s emotional needs and how we could support** them with compassion and kindness. MNRI¹ taught us the impact protective reflexes have on **one’s ability to mature and integrate the primary reflex motor patterns.**

Involving Integrative Therapies = Being Counter-Cultural

Even with all the progress that has been made over recent decades to make Integrative Therapies available, there remains a prevailing attitude that Western Medicine provides the best tools and solutions for children with medical complexities. This is reflected by insurance **coverage and Western Medicine providers’ attitudes, lack of knowledge, trust, and relationships** between the two worlds. The former is evidenced by limitations in coverage. For example, my child can receive massage therapy as an inpatient while under the care of a physician, but not by the same massage therapist in-home. Therapies like acupuncture and Reiki, despite being around thousands of years, are not covered. The latter is starkly seen within facilities where Integrative Therapies are offered, but Western Medicine providers are not making referrals.

¹ Masgutova Neurosensorimotor Reflex Integration (MNRI)

When parents venture even a little way beyond these boundaries resistance easily surfaces. Get even deeper into the vast world of Integrative Therapies, layer in multiple facets of a child's medically complex needs, and parents easily become viewed as radical. We have to navigate **which providers are "safe" to talk about our use of Integrative Therapies with and which ones to avoid** the conversation completely. Even at best, a safe provider will make a list of which Integrative Therapies we are using and maybe a general idea of why.

When it came to Levi's providers (20+), my husband was always amazed at how I could keep track of each one's medical specialty, personality, relational-style, and their level of openness to Levi's robust toolbox. The later three factors had a significant impact on what I shared during our clinic visits and how much I unearthed concerning the full picture of Levi's needs, challenges, and successes.

Deeper discussions were often missed about our use of Integrative Therapies, their benefits, challenges, and interfacing with tools sourced from Western Medicine. As a result, both of us, parents and providers, lost out on having **a complete conversation about my child's care**, learning something new, and collaborating on what could be most helpful for Levi.

Within the world of Integrative Therapies, one of the challenges parents face is finding providers who are comfortable working with our children because of their medical complexities. Finding an acupuncturist who works with children is one thing, finding one who will work with our complex child is different. Finding that provider within driving distance or who can come to the home narrows the pool even further. Because there are a limited number of these providers, they tend to see lots of kids with complexities, therefore wait lists ensue. Because insurance **companies don't cover these services, only families who can pay out of pocket** or navigate waiver resources are able to get access.

Until all of these factors can improve, parents will continue to be counter-cultural when involving a range of Integrative Therapies as tools in the care of their child with medical complexities.

Parents = Cross-Cultural Care Coordinators

Western Medicine with its silos of sub-specialties requires parents of children with medical complexities to be excellent at care coordination. Palliative Care and maybe an open-minded Pediatrician or Pharmacist or Specialist are the only unbiased support a parent has available when the silos of specialists are offering competing opinions and unable to view the child as a whole-person.

Add into the mix the use of Integrative Therapies and it becomes a cross-cultural situation where parents are required to navigate multiple ways of talking about health/wellness/medicine, translate for others, and manage variables that go far beyond the norms of parenting. Daily parents are reaching into their robust toolbox sourced from Western Medicine and Integrative Therapies. Navigating which tool to use when, understanding its benefits and limitations, how best to integrate it, what to do when it



conflicts with other tools, the process of shifting from one to another or utilizing multiple tools simultaneously; all while navigating the ever-**shifting terrain of their child's medical** complexities and symptom management.

Most of the time parents are genuinely alone in navigating the role of being a cross-cultural care coordinator for their child. It is an overwhelming and easily isolating experience. It is a rare and highly meaningful experience to be able to discuss ways in which we are utilizing tools and resources within the worlds Western Medicine and Integrative Therapies. Most of these conversations happen with other families. Providers who are able to work within the scope of their practice while also including these cross-cultural conversations offer substantially more value to the care of our child than providers who don't. **Deeper levels of trust are** developed, and parents are more likely to seek out the counsel of these providers when challenges arise.

In our situation for a few years, we enjoyed the rare blessing of having cross-cultural care coordination conversations with a multi-trained Integrative Therapy provider who was also a Naturopathic doctor, an RN in adult home care, and a parent of a child with special health care **needs. Together we could honestly discuss and navigate the many tools in Levi's toolbox,** recognizing the benefits and limitations of them all.

I had no idea, two weeks into motherhood, a simple question about acupuncture to an NICU physician would lead me toward becoming a Cross-Cultural Chief Puzzle Master for my son Levi. As much as I perceived myself to be open-minded and cross-cultural at the time, ahead of me lie a steep learning curve involving much curiosity, humility, and grace. Each of the 20+ Integrative Therapy modalities we utilized for Levi expanded our toolbox and transformed our ability to provide him with genuine whole-person care. I am most thankful for the providers, on both **sides, who could welcome and embrace the "other" world. In the process, all of us have grown as** people and expanded our understanding of what is possible for our children with medical complexities when we welcome genuine cross-cultural collaboration.

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ESSENTIAL OILS: SCARLET'S STORY

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Caring for a child with a complex medical condition is challenging, especially when the level of care required is that of a hospital intensive care unit for daily life. For our daughter Scarlet, this was the case. Her syndrome was severe from birth and the learning curve was quick with little **room for error. When essential oils (EO's) came into our lives through a family member, we** were hesitant at first to believe that the benefits of essential oils could actually help someone, especially someone as severely challenged as Scarlet. We bought a few for respiratory support to **try with the mentality of "it couldn't hurt."** The more we used them and learned about their therapeutic properties, however, the more we began to see how they could be an asset to the care we were already providing. When Scarlet eventually went on a waiver and we discovered we could add essential oils to her budget, we were able to incorporate them into her everyday routine.

Scarlet's syndrome was degenerative in nature and nearly every major body system was affected. She suffered from frequent urinary tract and kidney infections, constipation, a host of severe neurological symptoms, and a weakened respiratory system. In order to treat all of the various symptoms she had in relation **to these, we used EO's as an addition to her many medications** and other medical equipment interventions.

Since we had in-home nursing care, we needed to acquire an order for our nurses to be able to use oils with Scarlet. Our palliative physician was very **supportive of our desire to use EO's and** so we got an order with ease and quickly began finding new ways to use them for her benefit. We also began using oils for the rest of the family because we were able to see how useful they could be. The various **respiratory oils became a first line option for my son's nighttime asthma** coughing episodes and we noticed a big difference in their duration.

The three primary categories we focused on for Scarlet were respiratory symptom management, illness prevention, and comfort care. The chart below gives a brief overview of how we liked to use oils with Scarlet. These uses are what worked for her and us specifically, but it may provide ideas to experiment with. There are oil references guides and apps that can be downloaded that go into much more depth about uses, application recommendations, and dilution ratios. I would highly recommend investing in one of these tools when using any oils. They will provide safety guidelines and tons of other useful information. Most **often we diluted EO's in a carrier oil.** Diluting in a carrier oil makes oils safe for use when applied to the skin. Oil companies such as **Doterra and Young Living have their own carrier oils for diluting EO's and there are a variety of** other oils to choose from as a carrier as well. Using a reference tool, such as a book or app, you can determine how much each oil needs to be diluted. Ratios or amounts will vary for adults and children and method of use, such as if it is applied to the skin or diffused.



Scarlet's Essential Oils Usage Guide

Essential Oils	Comfort: Pain Management	Comfort: Calming/Relaxation	Comfort: Constipation	Illness Prevention	Respiratory Symptoms
Pain Blend	X	X			
Peppermint	X		X		X
Respiratory Blend					X
Eucalyptus					X
Immune Blend				X	
Tea Tree				X	
Lavender	X	X			
Stress Blend		X			
Sleep Blend		X			
Digestion Blend			X		

*Below is a more in-depth description of how and when we used oils on a daily basis. *

Comfort Care:

Pain Management:

For pain, Scarlet's nurses or I often used a pain blend or peppermint. They could be applied topically to any area with pain, but we most commonly diluted them in carrier oil and rubbed **them into the bottoms of her feet with a roller bottle. Since it is unknown how EO's can affect seizures, we were always cautious with where we put them.** We applied these as part of her daily routine for any pains that may not have been noticeable, as well as needed for days when more pain was visible.

Calming/Relaxation:

Using EO's, as part of Scarlet's comfort care routine became one of our greatest assets. Many times, if we could reduce discomfort, other symptoms would resolve on their own. Some of our favorite oils to use were lavender, a stress blend, and a sleep blend. All oils were diluted if **applied directly or else they were diffused. These EO's were most often applied to her chest on her bath days in a steamy bathroom or at bedtime to aid in relaxation and restful sleep.**

Constipation:

Diluted, peppermint or a digestion blend was used on her tummy when constipation was a concern for discomfort.

Illness Prevention:

Daily we would apply an immune blend diluted in carrier oil on the bottoms of her feet. During times of illness we would also diffuse a couple of different immune blends along with other oils with germ killing properties such as tea tree. When illness struck Scarlet all of our **oils'** routines ramped up along with her medications.

Respiratory Symptom Management:

Scarlet was often congested and needed to clear many secretions throughout the day and night. **Our most common EO's during these times were a respiratory blend, peppermint, and eucalyptus, for their cooling and soothing effects and ability to help open airways. These EO's** were often diffused and/or applied directly to her chest depending on severity of symptoms or if she was resting. A favorite time to use these oils was in a steamy bathroom after showers. The moisture in the air loosened secretions and the aromas helped open up her airways so she could move secretions out. These were also commonly used in conjunction with scheduled respiratory treatments. These oils were perhaps the most impactful oils we used and what got us started **using EO's in a therapeutic capacity.**

Lessons Learned:

Comfort, and using the least invasive treatments wherever possible, was always our primary goal for Scarlet. Over the years our family and medical team became very proficient at using essential oils and reading her needs. As a nonverbal child, we relied heavily on years of experience with Scarlet to recognize the subtle changes she displayed as her way of telling us something was not right and that an intervention may be needed. Essential Oils became an invaluable tool in our arsenal to provide this level of care for Scarlet throughout her life. I truly believe this intervention improved the quality of her life as well as lifted the spirits of the caregivers around her. In the direst of times, when little could be done to comfort her, we had something to empower us in her care in a way that medical interventions could not due to their strict parameters. And the calming, invigorating, and soothing side effects were often a secondary benefit to caregivers in stressful times.

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EXPRESSIVE THERAPY AT **AKRON CHILDREN'S HOSPITAL**:
A CREATIVE REFUGE FOR HEALING

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The Emily Cooper-Welty Expressive Therapy Center (ETC) is a program of the Haslinger Family Palliative Care Center, under the directorship of Dr. Sarah Friebert. The Expressive Therapy **Center at Akron Children's Hospital was inspired by a palliative care patient, Lauren Ellen Gartner** who, with her friend, Maddie, used creativity to help her cope with a long illness. Inspired by Lauren and Maddie, Dr. Sarah Friebert spearheaded the creation of the Expressive Therapy Center. Named for Emily Cooper-Welty in honor of her foundational donation, the center received additional crucial financial support from a number of significant contributors and continues to receive significant support (financial and in-kind donations) from the community.

Located on the Akron Children's Hospital main campus, the ETC replaced an outdoor play area on the roof. The play area was underutilized, especially because of the impractical northeast Ohio weather. It soon became something else entirely: a place of inspiration, imagination, and **expression. The mission of the ETC is "To inspire hope and enrich lives by cultivating creative self-expression in a safe, healing, imagination-driven, family-focused environment that allows judgment-free expression of feelings and experiences" or "Create Heal Inspire" for short.**

The ETC opened in May of 2011 and provides holistic healing through the use of the creative and expressive arts. Expressive therapy is not a new concept: but by offering a completely dedicated **space in a hospital setting, is an innovative idea unique to Akron Children's Hospital. The ETC** is designed for patients, families, staff, and the community with the purpose of providing holistic healing through the arts. Currently, the ETC offers music therapy, art therapy, creative writing, and many other artist-in-residence style programming opportunities open to patients, families, and staff.



Play area prior to renovation.



Play area transformed into the Emily Cooper-Welty Expressive Therapy Center.

The ETC staff is comprised of a full-time music therapy coordinator, a full-time art therapy coordinator, a full-time office coordinator, a contracted creative writer in residence and a **contracted art therapist. In accordance with the vision of the center, “Expressive Therapy is accessible and integrated into healthcare for all.” Therapists provide** referral-based services throughout the entire hospital to patients and families while they are admitted to an inpatient unit, as well as providing procedural support and therapeutic services to patients and families in the Infusion Center and outpatient Hematology/Oncology Clinic. In addition, therapists also work with Palliative Care families, seen both in the hospital and through ongoing home visit sessions, providing support to patients and their families.

Expressive therapists have distinct training in specific areas. Art therapy is a mental health profession that uses the creative process of art making to improve and enhance the physical, mental, and emotional well-being of individuals of all ages (AATA, 2016). Art Therapists must complete an accredited graduate level program in art therapy which includes knowledge of assessment, art therapy theory and application, research, mental health assessment and treatment, group treatment, and ethics. They require a minimum of 850 hours of clinical and internship experience. Art therapists are certified on a national level with some states also offering licensure. Ohio is not currently one of those states. After completing 1,000 post graduate direct client contact hours with one hour of supervision for every ten hours of client contact an art therapist may qualify for the Art Therapist Registered (ATR) credential. ATCB also offers board certification to art therapists (ATR-BC). In order to become an ATR-BC, applicants must first successfully complete the ATR application process and then pass the Art Therapy Credentials Board Examination (ATCBE).

Art Therapy is a natural and non-threatening way for patients to express themselves. A trained art therapist uses art media and the creative process as a way to express feelings, reconcile emotional conflicts, foster self-awareness, manage behavior and addictions, develop social skills, improve reality orientation, reduce anxiety, and increase self-esteem. When a patient or staff member has the opportunity to create and process artwork, a natural distance is created from the intense emotion attached to the experience. Instead of talking about difficult feelings or experiences directly, something many individuals shy away from, they talk about the artwork created. By creating a representation of a thought, feeling, or experience, metaphor can often be found allowing for new insight and expression. Stress can be found throughout the hospital. Patients and families experiencing prolonged admissions, a new diagnosis of a chronic or life-threatening illness is both stressful for patient and provider, the pressure of meeting **productivity and “fitting it all in” to the work day, the death of a loved one, all of the secondary loss** caused by illness and injury, the list could go on and on. Art making with a trained art therapist can be a very transformative and helpful experience. The artist has completed and total control over the narrative of the artwork allowing for many positive outcomes. This might be a temporary escape into imagination and out of the hospital, reframing a negative thought into a new and more positive perspective, practicing mindfulness skills, or simply the powerful **experience of having one’s story witnessed by others.** All of the things mentioned are powerful tools for the individuals served in the hospital setting. Healing is not one size fits all. Utilizing other mediums like music, writing, dance, and movement allows the ETC to provide service that meets people where they are.

Another service utilized within the ETC is Music Therapy. Music therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program (American Music Therapy Association). Board certified music therapists are certified by the Certification Board for Music Therapists, have completed coursework and



earned at least a bachelor's degree in music therapy at an accredited college, and have fulfilled the required number of clinical hours and internship to sit for the board exam. In addition, music therapists are required to earn 100 continuing education requirements every five years to maintain their certification.

For children who have a difficult time communicating, or even understanding why they are in the hospital, music therapy can provide a safe space for the patient to express what they are feeling without words. An example might be drumming with a patient to help regulate their emotions or promote relaxation. Singing patient-**preferred songs provides a sense of “normalcy”** and familiarity in an unfamiliar environment. Exploring and playing different instruments provides opportunities to be creative **and “distract” from medical procedures.**

There are many benefits of music therapy, and there is much research that has proven its effectiveness. Music therapy has been shown to decrease blood pressure, regulate heart and respiratory rates, improve mood, improve communication and socialization skills, decrease **signs and symptoms of pain, and support a sense of control of one's own health and well-being.** Perhaps the most benefit comes from the patient's own experience of **engaging in music making** with the therapist. The therapist-music-patient relationship, when built on trust and rapport, can create a space for safe self-expression and positive experiences. Patients have reported **feeling “more relaxed” at the end of a session** and have exhibited more motivation to participate in daily activities of life and their medical care. Offering music therapy and other expressive therapies as part of the continuum of care contributes to the treatment of the whole person, **families, and the community at Akron Children's Hospital.**

A referral for services can be made by any hospital staff and families, who may also self-refer as they become aware of services through literature displayed throughout the hospital. There is a formal consult process in the electronic medical record, however verbal and written communication is always followed up by therapists to assess and coordinate services. Patients and families may be seen individually on a weekly basis, or they may have their treatment goals met by participating in therapeutic groups offered each week. Therapeutic services are goal directed and tailored to the unique needs of each patient and family and re-assessed on an ongoing basis.

Goals in expressive therapy treatment at ACH:

- Social stimulation
 - Normalization of hospital experience by meeting other patients and families.
- Cognitive stimulation
 - Planning and participating in a creative intervention.
- Sensory stimulation
 - **Using creative expression as a way to express one's thoughts, feelings, and experience.**
- Relaxation training
 - Calming anxiety through engaging in creative meditative experience.
- Opportunities to apply creative interests
 - Teaching skills.
- Procedural Support
 - Engagement with creative expression during difficult procedures.
- Stress management
 - Engaging in creative expression with a therapist can reduce perceived stress for patient and family.

- Addressing communication barriers or speech loss
 - Using creative expression to communicate what cannot be communicated verbally.
- Medical Compliance
 - Art/Music/Writing as a motivator.
- Psycho-emotional-spiritual support
 - Therapist is actively listening with positive regard, empathy, and without judgment.
- Pain management
 - Engaging and focusing on creative expression so that perceived pain is decreased.
- Creative Enrichment
 - Attending groups and supplemental expressive therapy activities.

Hearing directly from those who have utilized Expressive Therapy to increase resiliency and coping may be the most powerful way to understand the positive impact Expressive Therapy has had on Akron Children’s Hospital. **Below are just a few of the comments taken directly from patients and staff the ETC has had the privilege to serve:**

“Art Therapy made me feel like I was doing something, and I wasn’t just wasting away in a bed.”

“Art Therapy made me feel a lot happier and I felt a lot better because I was distracted and wasn’t focusing on how bad my stomach hurt or how bad my knee throbbed. I was able to escape for a little while and it felt amazing.”
-16 year old female oncology patient

“This is something I can add to my ‘can do’ list. It is something he (driver at fault) could never take away from me.”
-23 yo female car accident survivor

“It’s improved my work-life balance. I’m a coder, a medical coder, and we have quite a bit of stress in our lives—more and more as time goes on. And being able to come to this group and do some artwork has really actually helped me at home. It’s stress relieving here. It gives us something to look forward to. When I’m at home I’m doing different kinds of art than I ever used to do and that’s helping me to relax at home as well.”
-Adult, female, hospital employee

“This group has made me more relaxed in my job and creatively look for new solutions. I think it helps with enthusiasm and um just a positive attitude.” -Adult, female, hospital employee

The Expressive Therapy Center has been well received by patients and staff alike. Since 2011, the number of individuals and families that utilize expressive therapy services has grown dramatically; from 2018 to 2019 the number of inpatient families and children served alone increased 39 percent. There has also been an increase in the number of those participating in group therapy as well as staff support groups. The continued growth of Expressive Therapies at Akron Children’s continues to validate the value of services provided and the positive impact it has on healthy coping in both patients and staff. The center hopes to serve as an inspiration and model to other hospitals to encourage them to also “Create Heal Inspire.”

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CONCEALED VOICES: MUSIC THERAPY
FOR PEDIATRIC PATIENTS IN HOSPICE CARE

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We entered the home in the late afternoon. Mom called us earlier in the day and said something was just different and that D was in pain. But, unlike previously she **couldn't elaborate or offer** specifics. In many ways, the team felt like we had fulfilled all the wishes that D had before her death—we **helped them bridge the communication gap so that her voice wasn't silenced**, we made memories, and we facilitated the family's **reunion**.

D and I had instantaneous rapport over a love of laughter, fried chicken, and silly songs. It had been five months from her admission date and though she was trying to hold out for Christmas day, when the Social Worker and I entered, we knew that wasn't likely. In a home that was often filled with giggles and music, there was an uncomfortable silence, a palpable pain. Many friends and family were gathered, filling every nook in this small room. Mom was lying next to D in bed, trembling. Dad sitting in stillness under the window. At hearing our voices, D opened her eyes and connected with ours. Her fear and sadness penetrated through us. Many clinicians would **see this as a blurring of boundaries...but how do you not love on your pediatric patients...a 4-year-old** for whom life will end within hours or days. I maneuvered my way to the bed, placed **my hand on her foot (her favorite "tickly" spot), and watched her affect ease and shoulders lower**. My other hand found its way into her mother's, and I began to hum. *Baby Mine* came naturally, a lullaby her mother had heard in passing and asked for during a session once

*...From your head down to your toes
You're not much, goodness knows
But you're so precious to me
Sweet as can be, baby of mine...*

The Nurse arrived at that time and instinctively joined me in humming, a familiar experience with our very tight-knit team. In many ways that humming held the room; it provided a soundtrack to the pain and the beauty. We wrapped our metaphorical arms around D. As a Board-Certified Music Therapist (MT-BC), I was able to entrain to her respirations, matching the rhythm and cadence; and when mom or D presented with anxiety, the iso-principle offered an intervention to modify those breath patterns and restless somatic presentations back into relaxation and comfort. We never ceased the music, chaining from one melodic motif to the next, the music was the container that was grounding in the moment. After nearly two decades as a therapist at the bedside, I recognized our time was limited and so I made the clinical **decision to sing...to sing the pieces that framed D's musical biography...a surprisingly large number** for a 4-year-old. As our team made eye contact with the various family members, friends, and their community, they joined **in fulfilling D's last wish: to be surrounded by her songs when she "became an angel."**

Recognizing the sacredness of the moment, the music could serve another purpose. As hospice clinicians, we know that in most scenarios hearing is both our first and last sense, bookending



the cycle of life, and so we reminded those present that D could still hear us. I asked each individual, **“What would you want her to know? To remember of your bond? To hear at this time?”** As they offered their blessings and words, I reflected them through her favorite songs, including the ones we had composed together. Through this, they expressed their gratitude, they bid her goodbye, and echoed **“I love you.”**

What is it about music that makes it such a powerful tool? What was it for D and her family that turned a traumatic event into a beautiful memory? It begins with that physiologic truth that we reiterated to the family—hearing is our first and last sense, so intrinsically our experience of sound is universal. Because hearing develops in the womb, the sensation of hearing is also often aligned with a somatic presence—**our mother’s heartbeat, our own, the rhythm of our breath, of our walk...**even the sounds in nature have a timbre, cadence, and pitch. Imagine the call of a particular bird, cicadas in the night, or the sound of ocean waves as examples. But music goes beyond the physical, the gate control theory equates music as a stimulus as powerful as pain, and thus when used clinically can decrease or alleviate that experience. The neurologic implications are extensive as well, so much so that Oliver Sacks devoted his career to its study alongside Dr. Connie Tomaino, a music therapist and his colleague for decades.

The American Music Therapy Association defines Music Therapy as “the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program. Music Therapy is an established health profession in which music is used within a therapeutic relationship to address physical, emotional, cognitive, and social needs of individuals. After assessing the strengths and needs of each client, the qualified music therapist provides the indicated treatment including creating, singing, moving to, and/or listening to music. Through musical involvement in the therapeutic context, clients' abilities are strengthened and transferred to other areas of their lives. Music therapy also provides avenues for communication that can be helpful to those who find it difficult to express themselves in words. Research in music therapy supports its effectiveness in many areas such as: overall physical rehabilitation and facilitating movement, increasing people's motivation to become engaged in their treatment, providing emotional support for clients and their families, and **providing an outlet for expression of feelings.**”

When I sit at the bedside with patients and families alike, every decision I make can be supported from a physiologic, cognitive, emotional, spiritual, or psychosocial perspective:

When M, a 19-year-old with a hospice diagnosis of AIDS is agitated, held by her grandmother who has raised her since the death of her mother over a decade ago, and a devout Baptist asks **what Heaven may be like for her “baby,” I’m more likely to choose *Sweet By and By*** for its lyrical and faith affiliation rather than another random Baptist hymn.

And when P, a 32-year-old mother of two is struggling to say **“I love you” to her children, resulting from the brain tumor that has caused Wernicke’s aphasia, I might choose the *Barney Song*** (she has a 3-year-old) or **Irving Berlin’s *Always*** (which her grandmother used to sing to her) because the structure and simplicity of the music will motivate bridging the two hemispheres (where speech and music reside) so that creating a purposeful pause in the music will give P voice. In essence, a fill-in song which is manipulated by the Board-Certified Music Therapists’ behavioral, neurologic, psychotherapeutic, and expressive training that will serve as **the last verbal expression of connection for P’s children.**

Or when K, a 12-year-old whose family is not only afraid but also resistant to tell her she is dying **(and we know she's aware), I would take an indirect** approach and ask her which pieces of music she is most drawn to now, then provide a lyric analysis to the parents to demonstrate that she **knows and is too afraid/sad/worried to disclose that to them. It's Akon and Michael Jackson's *Hold My Hand***, by the way, which was released after his death so there are many layers that can be approached with great efficacy.

Or when C, a 7-year-old with a brain tumor that has rendered her deaf yearns for connection because her decline has minimized her time in the playroom to interact with her friends (and the other pediatric patients), I place the guitar upon the various parts of her body and encourage her to help me strum with a hand-over-hand motion to maximize her success or use a balloon against her cheek or heart while we both sing to exploit the vibrations as a replacement to the hearing she cannot receive.

Just spend five minutes with a music therapist and they'll impart innumerable stories about the privilege in bearing witness at the bedside with patients and families like D's.

Mom was the last to speak but could not express herself verbally, so our team led with *Silent Night*, **knowing that we'd have to make Christmas for them in that moment. We left the room in peace, quiet, and calm**, when it seemed appropriate to do so. At five in the morning I received the call. It was mom, she repeated almost chant-like:

*Silent Night, Holy Night
All is calm, all is bright.
'Round yon virgin mother and child,
Holy infant so tender and mild;
Sleep in Heavenly peace, sleep in Heavenly peace*

"I couldn't stop singing because it calmed me...she took her last breath 'in Heavenly peace, in Heavenly peace.'"

** Dedicated to the patients and families I have been honored to serve and journey with. **

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Themes of Songs Listed Above:

- *Baby Mine* – **originally from Disney’s *Dumbo*** and reflects on the challenges that a unique child may face but the love that is still felt strongly by the mother.
- *Silent Night* – traditional Christmas carol.
- *Sweet By and By* – traditional Christian hymn, often part of the Baptist liturgy. Lyrics focus upon visual imagery related to the idea of Heaven. The text further alludes to the **belief of reunion in the “sweet by and by.”**
- *The Barney Theme Song (I Love You, You Love Me)* – **from the children’s television series** and reflects the bond between families and friends.
- *Always* – composed by Irving Berlin in 1925 for his wife. Lyrics address the promise of presence through all of the cycles and experiences in life, good and challenging.
- *Hold My Hand* – Duet between Michael Jackson and Akon released posthumously in 2010. Refrain emphasizes the need for presence and support. One of the verses specifically focuses on the finality of death and transience of life, and notes a feeling of darkness if one feels alone or isolated.

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COMPLEMENTARY AND MIND-BODY PRACTICES FOR SYMPTOM MANAGEMENT WITH CHILDREN AND ADOLESCENTS

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There are a large number of integrative therapies used with children and adolescents during palliative care to help manage symptoms such as pain, anxiety, or stress. Mind-body practices are one type of therapy that may be used for symptom management in children and adolescents receiving palliative or hospice care. A mind-body practice may be anything that takes the mind away from suffering. These techniques may be practiced alone (listening to music, watching TV, meditating, prayer, doing a craft such as knitting or painting) or in a group (doing a yoga or tai chi class), self-administered (self-hypnosis, acupressure, deep breathing) or provided by a professional (acupuncture, hypnosis, music or art therapy). Children are generally open to participating in these types of activities and the activity chosen will depend on the age and developmental level of the child (Doellman, 2003). In this article we discuss several mind-body practices, the scientific evidence relating to each, and how they can be helpful for children and adolescents receiving hospice or palliative care.

Professionally Delivered

Hypnosis and Self-Hypnosis

Hypnosis **can be described as an “alternative state of awareness” that causes our mind to focus** on something on purpose so that we are not focusing on another unpleasant idea or sensation (Friedrichsdorf & Kohen, 2018, p. 137). One explanation of the ability to be hypnotized or use self-hypnosis is the ability to become engrossed in a fantasy world or a focused use of imagination (Hilgard, 1974). A recent systematic review reported on five studies that used hypnosis to help children cope while going through painful procedures such as lumbar punctures and bone marrow aspirations (Thrane, 2013). One study found that children ages 3 to 8 years who were highly hypnotizable had significantly less pain and anxiety using a hypnosis intervention during venipuncture while children who had low hypnotizability had significantly less pain and anxiety during a distraction intervention (Smith, Barabasz, & Barabasz, 1996). In three separate studies, Lioffi and colleagues tested hypnosis with children ages 5-16 years in three group randomized trials for lumbar puncture, bone marrow aspiration, and venipuncture: in all three trials hypnosis was significantly better than usual care which used the topical numbing cream Eutectic Mixture of Local Anesthetics (EMLA) (control group) and better than EMLA plus attention (attention control group) (Lioffi & Hatira, 1999; Lioffi, White, & Hatira, 2006, 2009). To read a thorough and well-referenced description of the use of hypnosis and self-hypnosis in children and adolescents receiving palliative care, please see the article by Friedrichsdorf and Kohen published in the *Annals of Palliative Medicine* (Friedrichsdorf & Kohen, 2018).

Acupuncture

While not a mind-body practice, acupuncture can be a good complementary therapy for nausea, pain, and other symptoms. Acupuncture has been used in traditional Chinese medicine for over 2000 years. Acupuncture uses fine needles to stimulate particular points on the body thought to change the flow of energy in the body. A more modern explanation is that the needles stimulate the muscles and nerves near the acupuncture point, releasing neurochemicals (Brown, Rojas, & Gouda, 2017). There have been a large number of studies on this subject with adults but fewer studies with children. Studies with children have shown that acupuncture seems to be at least somewhat helpful for pain, while other studies have shown acupuncture to be very helpful for both post-surgical and post-chemotherapy nausea and vomiting (Jindal, Ge, & Mansky, 2008; Kemper et al., 2000). Jindal and colleagues found 8.3% of patients experienced an adverse event (an injury as a result of treatment). Overall, acupuncture has been well received by children for symptom management and is safe as long as administered by a well-trained and certified practitioner using clean technique and sterile, single-use needles. Children who are immunodeficient or have a low platelet count should consult with their physician before receiving acupuncture.

Group Movement Classes: Yoga

Yoga is a practice that combines movement, poses, purposeful rhythmic breathing, and relaxation. A trained yoga instructor is able to adapt poses and movements for almost any level of physical ability. Yoga may be done on a mat, in a chair, or even lying on a bed. Several studies or structured programs have been done with children with chronic pain or serious illness. One study with children ages 7 to 21 with cystic fibrosis showed significantly less anxiety with each session and significantly less joint pain over the course of the six-session study as well as non-significant improvements in respiratory symptoms, general pain, and sleep (McNamara et al., 2016). A small study provided two yoga sessions per week for 12 weeks to eight children with cancer ages 5 to 17: The study found significant child-reported improved health-related quality of life and significant parent-reported improved health-related quality of life as well as significant improvement in psychosocial, physical, and school-related quality of life (Wurz, Chamorro-Vina, Guilcher, Schulte, & Culos-Reed, 2014). According to the National Center for Complementary and Integrative Health, yoga is safe when practiced with a well-trained yoga instructor who will adapt poses when needed (National Center for Complementary and Integrative Health, 2017).

Self-Administered or Parent-Administered

Apps for Relaxation

Many parents use their mobile phones or devices to distract infants and young children with favorite videos or games, but newer applications (apps) for mobile devices are specifically meant to be soothing, relaxing, or actively help with meditation or mindfulness techniques. A recent systematic review examined free apps that were relaxing and calming and divided these apps into two categories: (1) relaxation apps meant to promote relaxation through mindfulness, yoga, or other relaxation body movements, meditation, self-hypnosis, or the like; and (2) distraction apps that promote distraction or relaxation through entertainment such as games or calming music or images (Weekly, Walker, Beck, Akers, & Weaver, 2018). The group found one app for infants to preschoolers called *Breathe, Think, Do with Sesame* (Sesame Workshop, 2016), several apps directed at elementary-age children and above including *Breathe2Relax* (National Center for Telehealth & Technology, 2016), *Smiling Mind* (Smiling Mind, 2018), *Calm*



(Calm.com, 2018), *MyCalmBeat* (MyBrainSolutions, 2015), and *Headspace* (Headspace, 2018), as well as a more advanced app for adolescents or parents with anxiety called *Mindshift* (Anxiety Disorders Association of British Columbia, 2017). Two award-winning apps that parents, grandparents, or other adults and children can do together over the internet include *Kindoma Drawtime* (Kindoma, 2017a), and *Kindoma Storytime* (Kindoma, 2017b).

Listening to Music

Listening to music is an activity that most people enjoy. Listening to music is distinctly different from participating in a Music Therapy session (although the terms are often used interchangeably), which is interactive and involves a highly educated and trained Music Therapist. Please see the American Music Therapy Association (musictherapy.org) for a more thorough description of Music Therapy. Listening to music can transport children and adults alike into a different state of mind: upbeat, excited, calm, focused, or other emotional states. One study of note involved children ages 7 to 12 years randomized into either a music or no-music intervention during a lumbar puncture. The study found a significant decrease in pain during and after the procedure and significant decrease in anxiety before and after the procedure by child self-report (Nguyen, Nilsson, Hellström, & Bengtson, 2010). The children reported ***“I felt calmer...,” “I liked listening to the music,” “I just focused on the music... it helped”*** (Nguyen et al., 2010). A simple thing like listening to music through headphones can help children cope with a painful procedure.

Meditation

Meditation is a practice of awareness in the present moment or “thoughtless awareness” (being aware of the present moment without thoughts). This perfect state of awareness can be difficult to achieve and **maintain, which is why people “practice” meditation rather than just “doing”** meditation. There are several types of meditation that can help people achieve this state of awareness including mindfulness-based stress reduction (MBSR, learned during a formal eight-week program), transcendental meditation (repetition of a mantra or word during the session), and mindfulness meditation in which generally focuses on the breath (inhalation and exhalation) while sitting quietly.

Numerous studies on meditation have been conducted as well as several systematic reviews and meta-analyses. In a meta-analysis, the statistics from a group of studies are combined to give a result as if all of the participants had completed the same study; this gives stronger scientific evidence. One meta-analysis of adult cancer patients (mainly women with breast cancer) found that MBSR was moderately helpful for mental health (stress, anxiety and/or depression), but only minimally helpful with physical health (Ledesma & Kumano, 2009). Another meta-analysis looked at randomized controlled trials involving any type of meditation with adults; the authors were interested in stress-related outcomes including overall mood, anxiety, depression, sleep, and pain (Goyal et al., 2014). The meta-analysis included 47 studies and 3,320 participants: The analysis found that meditation moderately improved anxiety, depression, and pain, a small improvement for stress and mental-health related quality of life, and little to no improvement for mood or sleep (Goyal et al., 2014). One systematic review was conducted looking at meditation and other mind-body therapies with children up to 18 years old with a cancer diagnosis: the authors were not able to complete a meta-analysis because the studies did not look at the exact same things (Velez-Florez et al., 2018). This review found that meditation was moderately beneficial for children with cancer for stress, anxiety, depression, quality of life, and sleep in addition to decreased number of pain medication doses (Velez-Florez et al., 2018). None of the studies found any adverse effects for meditation. Given the minimal risk of meditation

and the potential benefit to children and adolescents in palliative care, meditation may be worth a try.

Conclusion

Overall, given the minimal risk and the wide variety of techniques discussed in this article, there should be something that appeals to all ages and cognitive abilities. Many of the approaches described can be tried without any formal class or professional intervention. Others, such as hypnosis and especially acupuncture require a professional to administer. While Yoga can be attempted without a class, it is better to learn with a certified yoga teacher who can provide adaptations to movements and poses for the safest and best experience. Meditation may best be learned with the help of a teacher but can be safely practiced without. Listening to calming music or using the apps for relaxation are solitary ways of achieving a relaxed state. When a child or an adult for that matter is able to relax, symptoms such as pain, anxiety, fatigue, sleep, and stress decrease.

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ACUPRESSURE AND OTHER COMPLEMENTARY THERAPIES FOR SYMPTOM MANAGEMENT IN PEDIATRIC PALLIATIVE CARE

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Parents of children who are suffering for any reason simply want their children to feel better. Pediatric Palliative Care provides the framework that allows this to happen. Whether or not root causes can be eliminated, we utilize tools for parents and patients through listening and acknowledging, while marshaling our resources creatively to impact the situation from every angle: spiritually, mentally, physically, and in the context of family and community.

Practitioners of western medicine have many tools that work very well in the acute settings: medications for underlying disease, pain, respiratory symptoms, anxiety, nausea, vomiting, depression, surgery, chemotherapy, and so on. When curative therapy fails, or a patient has a chronic illness that is not addressed adequately by the acute medical setting, palliative care teams can often help children and families cope with the burden of care.

Families and patients often turn to comfort care measures outside our scope of practice such as aroma-therapy, hypnosis, cupping, acupuncture/acupressure, massage, meditation, vitamin therapy, herbal remedies, CBD oil, marijuana, and other **“magical cures” that are found on social media**. It is incumbent upon us to be knowledgeable about these modalities in order to help our patients and families to utilize them wisely. There are many resources to help us to understand which of these therapies will help a child and which do not, and worse, may cause harm and perhaps rob families of precious resources.

We must strive to have a working understanding of each modality and, if possible, an experiential understanding. We should develop a working relationship with the people providing services to the families in our community. We should understand both cost and outcomes, in order to refer a child confidently.

In my own practice, I use breath work, self-hypnosis, acupressure, mindfulness meditation, Reiki, and massage. I maximally incorporate child life services that have available guided imagery, music therapy, pet therapy, aroma-therapy, clowns, and other volunteers who interact with our children. I refer out to other professionals in my community when these complementary modalities fail to provide enough support to a child or family.

I strive to teach multiple modalities to parents and children to serve as bridges for the children until relief is found or more effective medical therapy is forthcoming. I always stress that **non-pharmacological therapy should be a parent's first choice to treat a symptom, since these rarely cause side effects, can be done anywhere, and cost nothing once a child had developed the competency to use the tools that we (parents and team) have taught them.**



With modalities such as breath work, self-hypnosis, and mindfulness meditation, the locus of control becomes internal rather than external. Given that children are rarely given control over much once they enter a hospital or clinic, having mastery over pain and other symptoms through using these techniques can allow a sense of calm and ease as a child moves through the medical system and their therapy.

Breathing

The first thing I do with a child is entrain to her breathing as I examine her. Children are natural at this. Once she looks at you, you can easily get her to breathe along with you, and as you slow your own breathing, she will copy your breathing and slow down her own. Younger children do this automatically, older children, teens and young adults require more work to allow this to happen. This also works to settle a child down quickly and engender connectedness and trust.

Hypnosis

After learning to control breathing, children can then learn self-hypnosis in various ways, depending on their age. For younger children, I use my voice in a hypnotic way to help ease anxiety and teach children techniques such as the Magic Glove (1) and the Pain Switch. I also **use books such as “Harry the Hypno-potamus” (2) and other** scripted stories for younger children as a way to teach self-hypnosis through stories. The use of scripted stories has served me well for many symptoms at a variety of ages. I am often told my voice will put anyone to sleep!

When more sophisticated hypnotherapy is called for, advanced training in hypnotherapy is required (3). Depending on the age and abilities of the child, one can work on symptoms such as nausea, vomiting, severe pain, or whatever symptoms they may have, including anxiety, sleep disturbance or other phobias associated with treatment using this modality. I have used self-hypnosis for gut-directed therapy in children who has irritable bowel syndromes, post-chemotherapy changes in their gut function and have simply tuned out of their guts normal functioning due to stress.

Acupressure

One of my favorite things to do with children and families is to teach them acupressure points. I use multiple points for pain, relaxation, anxiety, nausea, constipation, sleep, and urinary retention after surgery or associated with narcotics. I also teach them to new parents to help with colicky babies. I explain the use at least two different points. The use of multiple points together tends to improve the success rate of this practice. Acupressure is also a way for parents to touch their child therapeutically, providing comfort and relief of symptoms. The more that these techniques are practiced, the more effective they become. This can also open a sacred space for parents and children to dialogue about the process of healing. These points also temporize while waiting for medications to arrive or to take effect, or even to take the place of medications altogether. I usually start each session with a bit of relaxation, deep breathing, and massage to maximize the efficacy of acupressure.

Parents need to remember that the amount of pressure and length of stimulation varies with the age and the condition of the child. Infants respond very quickly while older teens need a bit more pressure and more time. It will take a bit of experimentation to use these techniques optimally for each child. I would recommend that practitioners gain some expertise with these

techniques before trying them on patients. I have found that friends are always willing to be recipients of this practice when you are learning!

Below are listed the points I use most frequently (4). When I refer to the finger widths below, I **am referring to the child's own fingers. I often use gold beads that are placed with tape and** children usually auto-stimulate them after placement. These are particularly helpful on the ears (4). You must be careful as some children may swallow them or choke on them also. I do recommend that you find a book or look on the internet for the location of these points. They are easy to locate once you have seen a picture of them.

Large intestine 4: located in the fleshy webbing between the index finger and thumb. It is an all-purpose point used to treat problems of head and neck, breathing problems, abdominal problems, and constipation.

Large intestine 2: It is located on the outside of the index finger, on the joint where the finger meets the hand. It can relieve colic in babies, treat eye disorders, toothache, sore throat, gum inflammation, and reduce heat from the body.

Bladder 47: Located on the back, midway between the hipbone and ribcage, in the muscle just off the spine. It can relieve colic, chest congestion and breathing problems, diarrhea, and vomiting. It is also good for back pain.

Pericardium 6: It is located three finger-widths below the wrist and between the two tendons on the inside of the arm. This helps with nausea, abdominal pain, digestive issues, and calms the mind. It is best employed with slow breathing, a fan to the face, and, once used on one side, proceed to use the other side.

Liver 3: It is located in the fleshy webbing between the big toe and the second toe on top of the foot. It helps with headache, dizziness, vertigo, insomnia, congestion, eye pain, swelling, and depression.

Spleen 6: Located three-finger widths above the inner anklebone. It helps with digestive issues, menstrual problems, edema, infertility, skin disease, insomnia, headaches, dizziness, and lower body pain.

Stomach 36: Located four finger-widths below the kneecap and one finger-width towards the outside of the shinbone. This location will help with constipation, gastric pain, vomiting, hiccups, diarrhea, and leg pain. It will also improve immune function and overall body strength.

Kidney 3: Located on the inner side of the foot by finding the uppermost point of the inner **anklebone and sliding towards your Achilles' tendon. Stimulation at this point treats colic, male** infertility, lumbar pain, irregular menstruation, headache, vision problems, toothache, asthma, cough, sleeping problems, and diabetes.

TW5: It is located on the outer side of both arms, three fingers above the wrist crease. This soothes gum pain, boosts the immune system, and relieves wrist and shoulder pain.

Lung 9: It is located on the palm side of the wrist crease, under the thumb. This is effective for teething in babies, asthma, cough, runny nose, and palpitations, as well as local wrist pain.

Stomach 3: Located on the outer side of the nostril along the cheekbone, on the lowest point on the bone. This relieves toothache, facial paralysis, swelling of lips and cheeks, and twitching of eyelids.

Small intestine 18: Located at the lower border of the zygomatic bone, right below the outer canthus. It is useful for twitching of eyelids, facial paralysis, toothache, and swelling of the cheeks.

HP3: Is found on the upper arm just above the elbow crease, towards the inside of the biceps tendon. This point will relieve colic, treats anxiety and stress, chest and stomach discomfort, and local arm and elbow pain.

Gall bladder 20: Located at the ridge of the occipital bone, midway between the ear and the spine, between the two joining muscles. This point is useful for enhancing the release of endorphins and promoting restful sleep. It treats fevers, stiff neck, vertigo, headaches, eye problems, and shoulder and upper-back pain.

Spleen 4: Located on the inner side of the foot, one finger width toward the back of the foot from the base of the big toe. This point is good for helping babies sleep, relieving abdominal pain, food poisoning, menstrual problems, heart and chest pain, and insomnia.

To help calm children, I will use gentle massage of points on the head. I will start with my fingers on the temples and apply gentle pressure in a circular motion just off the outer edge of the eyebrows. I place my thumbs at the hairline just above the nose and apply gentle pressure. I will also place my hands, palms open, one on their forehead, and one on the back of their neck and just apply enough pressure to help them feel as though I am actually holding their head in place. It seems to comfort children and adults when they are feeling anxious.

For sleep or anxiety, I use the divot just above the nose and between the eyebrows. At the same time, I will stimulate the point directly above both ears and in line with the nose at the top of the head. You should feel a slight depression there. As you gently stimulate these points and lead the child through a series of deep breaths and relaxation exercises, sleep is not far behind. I often see the parents drift off to sleep as they follow along as well!

As the parents master these techniques to help their children, they feel calmer and empowered at a time when the whole family is very vulnerable. These techniques combined with a sleep ritual that may include aroma-therapy and some gentle exercises promote sleep hygiene. When I do use aroma-therapy, I get advice from the service in my hospital and also refer to a text on essential oils that I enjoy (5).

Meditation

More recently I have started to use mindfulness meditation (6) with teens and young adults, although it also works with children of all ages, as do yoga poses. There are more and more apps and availability of classes for people to learn these techniques. I find it very powerful for everyone to learn to focus their minds at times of great stress (7,8). I recently saw a great TED talk on Bite Sized Mindfulness that shows me how I can easily incorporate it into my everyday encounters to help even the most stressful encounters to make a difference (9).

There is wheelchair yoga with breath work that can be practiced in the hospital as well and, when these techniques are practiced over time, can be very helpful with existential pain and



suffering. These modalities can also be used with parents and be translated into the home for ongoing comfort and healing (10).

I hope that, as your practice grows, you will be inspired to learn new modalities to bring to these very special children, as I have. Being able to inspire young people to find their path to healing is what keeps my faith in our complex world alive.

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PEDIATRIC MASSAGE THERAPY

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Pediatric massage therapy is not like getting a massage at a spa. There are no fluffy bathrobes or **cucumber slices for your eyes. It doesn't generally take place on a massage table or use exotic massage oils.** It takes place in a hospital bed, with a young patient who may have ports or tubes or trachs, leaving very little body surface to work with. The hospital can be a scary, demanding place for a young sick child. Massage therapy is one of the few instances where it is up to the **child if they want to accept or reject treatment. It can be empowering for them to say "no," one day and "yes," the next. They can direct the massage therapist to what part of their body they want worked on, and what's off limits.**

A massage therapist can be a great addition to a Palliative Care Team. Massage therapy used to be the province of nurses, but as care became more technical and concerned with computers and **managing complex IV's, there is less time for hands-on care.** Tina Allen, an Occupational Therapist and Massage Therapist created a Certified Pediatric Massage training for working in **the hospital setting. Her amazing organization, "Liddle Kidz Foundation," sponsors Certified Pediatric Massage trainings all over the world, taking massage therapists into orphanages and hospitals in many underserved countries.** The power of touch can help ease pain and anxiety for **children in many different settings. Her "nurturing touch," is a simple yet powerful way to treat children, using a broad open palm and a gentle but firm touch.** She has detailed trainings for different settings like the NICU or working with children with Autism. She has truly opened the doors of many hospitals to the healing possibilities of massage therapy.

I am the senior Massage Therapist at the UCSF Osher Center for Integrative Medicine in San Francisco. I see my adult outpatients in the Osher clinic and I see my pediatric patients at the **UCSF Benioff Children's Hospital, San Francisco. I provide chair massage to the parents of the pediatric patients once a week, and chair massage for the nurses of Pediatric Oncology once a month.**

Thanks to the philanthropic "Pierre's Birthday Fund," for funding my position. Pierre's Birthday Fund was started to honor Pierre Schreyer who celebrated his 17th birthday at UCSF Benioff Children's Hospital, Oakland while undergoing treatment for stage 4 neuroblastoma. The foundation's goal is to improve the social, mental, and emotional well-being of hospitalized kids by enabling services that bring smiles to their faces and comfort them through pain management, including massage therapy.

I see many different kinds of pediatric patients. As a member of the Integrative Pain and Palliative care team (IP3), I am directed to who would benefit from massage therapy, based on morning rounds. Many of our patients undergoing chemotherapy have headaches and nausea. Acupressure, using finger pressure on acupuncture points, can provide relief, using points on the hands. Large Intestine 4 (LI4) between the thumb and the forefinger is good for headaches and Pericardium Channel 6 (PC6) about 3 fingers up from the wrist on the inside of the forearm. This is the point that sea bands (an elastic band with a bead imbedded in it) that drugstores sell for motion sickness can help. Hold with a steady pressure for 10-30 seconds, or until you feel a



pulse. Sometimes you can feel the energy more on one side than the other, and after you work the points for a few minutes, the energy evens out, and the patient feels better. A nice thing about these points is that patients can use them themselves and see if they have a benefit. I like to use the LI4 point when I go to the dentist. It gives me a sense of control over the pain I might be feeling in my mouth. The brain can only process so much pain at once. The new stimulus gets **the brain's** attention.

One of the many benefits of being a massage therapist is being able to show the parents a few simple massage techniques that they can use on their children. It gives them a modicum of **control in a situation where many feel helpless to help at all. It's a way to bond with their** children, without words, and gives the parents something to do while they wait during a long hospital day for the doctor to come or a long hospital night for the child to sleep.

Massage therapy can be a useful adjunct to other pain relievers. It can be used between doses of pain medication, and along with other pain medication. It can be especially useful when **tapering opioids. It doesn't interfere with other pain medication. It can be a good distraction,** and a powerful pain reliever on its own. One of the wonderful aspects of the massage therapy is it can lead to sleep, which is a blessing in the hospital setting.

We see many teenagers with pancreatitis, who undergo a procedure called ERCP, which clears their pancreatic duct. There is a lot of discomfort and abdominal pain. I have developed a massage protocol based on soothing the enteric nervous system, which innervates the intestines. Lying on their left sides, with a pillow under their neck, and a pillow between their knees, I start with a broad hand and trace a light counterclockwise circle along their mid and lower back, tracing the intestines. I repeat this simple stroke many times, as it lulls the nervous system to switch from sympathetic activation after the procedure to parasympathetic activation, the rest and digest mode. I can often hear bowel sounds, after just a few minutes of this stroke. I alternate with fingertip smaller circles, as I think about tracing the convolutions of the intestines. Oftentimes after this procedure, they fall asleep, which is where the healing begins.

I have had the privilege of working with babies in the NICU. My youngest patient was 30 weeks old; she was born at 24 weeks. I placed my hands into the isolette, and I could feel her energy **was very chaotic. I didn't actually touch** her, I just held my hands above her head and her feet until I could feel her energy flowing in a more cohesive pattern. I worked with her every week for the two months she was in the NICU, and I was fortunate to see her again, when she came back to the unit for a well-baby checkup as a one year old, smiling and happy. Working with babies, **you have to follow their cues, as to what they like and don't like. Avoiding any area that has** tubes, and generally avoiding the heel, where they have had a lot of heel sticks. If you place your thumb in their instep, you are stimulating their digestive organs. Lightly stroking their foreheads, will help them fall asleep.

Massage therapists can play a vital role in helping the nurses, the parents, and the patients dealing with pain and anxiety. As pain medicines come under scrutiny and hospitals search for alternatives, massage therapists are ready and able to help, with pain relief and relaxation.

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ENHANCING THE FLOW OF LIFE: THE PEDIATRIC PALLIATIVE AQUATIC PROGRAM

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Program Development, Impact and Benefits

The Pediatric Palliative Aquatics Program (PPAP) is a gentle, warm water modality designed to meet the needs of children with lifespan limiting conditions. It is especially beneficial for children who are medically fragile or approaching end of life. PPAP mirrors the goals of **palliative care**: *“to provide comfort and support, pain and symptom management and quality of life to children with life-limiting diseases and to their families.” (World Health Organization)*

The PPAP was piloted in 2006 by Sheila Pyatt, RN, at George Mark Children’s House, the first pediatric palliative care facility of its kind in the United States, located in San Leandro, CA. This Program invites participation of parents and other family members while encouraging normalization of life through aquatic activities. During a session, the practitioner creates space for a medically-fragile child *to experience support and movement* while submerged in warm (96°F) water.

Whether practicing swim strokes with a teen with cystic fibrosis or assisting parents during a session with their baby nearing end of life, palliative care goals remain the same. Aquatic practitioners use age-appropriate toys, soft lighting, and appropriate music or sound to meet the needs of each child. Occasionally, the delighted squeals of children playing in water can be heard all the way **to the nurses’ station!**

As the patient population began to include more children with complex medical conditions, practitioners refined their aquatic techniques to better meet patient needs. Skilled nursing assessment is essential, especially for this vulnerable population. Many children require continuous oxygen. Several have tracheostomies. Well-trained, skilled aquatic practitioners can safely accommodate almost all patients with these medical needs during aquatic sessions.

Sometimes, the most profound sound is silence. The aquatic practitioner frequently works in silence. She may observe as a young father tenderly holds his dying newborn in his arms, moving him slowly in the water and speaking softly while mother takes photos. Or, she may work beside him, helping him to position his son more comfortably.

During sessions with medically-fragile children, the aquatic practitioner may become acutely **aware she can do nothing to affect the child’s life trajectory. She can, however, profoundly affect the child’s journey during these final, sacred moments.**

Such an event happened The Day the Princess Sang:

Something about the princess forced one
To ignore all observations
Relating to her lineage



Speculations became suspended in mid-air
 With the realization that only the silent,
 Undescribed moment should exist.

The midwives knelt in the warm water,
 Rocking, humming,
 Anticipating a nativity.
 Shadows lengthened; water lapped gently
As the Princess' breathing quickened.

Her being radiated serenity
 While her eyes beheld
 Another dimension
The Princess's face became dusky
 As the shadows lengthened.
 A sudden burst of sound
 Fractured the silence.
 The princess began to sing!
 She sang her song in clear, sure tones
 For all the world to hear.

The message,
 One of triumph
 Of life lived, shared
 And just as swiftly,
 Surrendered.

As sunset streaked across the sky
 Her life force dimmed.
 Sound faded to silence.
 In one subtle, sacred moment
 The spirit of the princess took flight.

Reflection:

Prior to and after sessions, the role of patient care nurses is essential, especially when a child is dying. Nursing staff prepare the child before a session and tenderly assume care post session. When I learned that Princess had died two hours later in the arms of the evening shift nurse, I felt her journey had been peacefully completed.

This profound experience with Princess has remained with me for over ten years. I felt a deep connection with her sound. I toned and baby Princess answered, singing her life-song clearly during her last hours. The experience was beyond description. Princess has been a spiritual teacher for me. Today I wonder: is it possible the power of both the water and our love helped Princess to heal the wounds of abuse that caused her death?

Program Foundation: Influences and Principles of PPAP Development

In addition to the professional skills and life experiences of nurse aquatic specialists, the two programs described below provided the foundation of this program and contributed significantly to its development and implementation.



The Jahara® Aquatic Technique.

Using specific techniques based in Shiatsu massage, the practitioner applies precise support and **gentle traction to the client/patient's body, allowing the neuromuscular system to respond.**

These techniques result in *deeper relaxation and freer breathing* for many patients. The training Sheila received from Mario Jahara, a Brazilian Shiatsu master, became the mainstay of **her work. She learned to “let the water do its work” and “to follow the lead of the child” while** working slowly and precisely. *Focus, purpose, and intention* are essential during sessions. This technique works intuitively for children who are medically fragile or dying.

Special Needs Aquatics Program—SNAP During the years Sheila was studying the Jahara Aquatic Technique, Dori Maxon, a physical therapist, was simultaneously conducting her *Special Needs Aquatics Program* in the same pool. Sheila became an avid SNAP volunteer for over 12 years. Working in this program with children experiencing a wide range of developmental and emotional challenges, Sheila noticed similarities and differences in both populations. **When she started the PPAP at George Mark Children's House in 2005, Sheila** integrated the body mechanics and activities she had learned in SNAP with the principles of Jahara Aquatic Therapy. As patient acuity and fragility increased, working with gentleness and precision took on greater meaning.

Consistently Observed Outcomes Post-session

Palliative and nursing care staff have observed improved patient status, however brief, in many patients post session. These outcomes include:

- calmer, more relaxed behavior
- deeper, slower respirations
- relief of muscle pain and spasticity
- ability to move in ways not possible on land
- deeper, longer nighttime sleep

Equally important are the responses of family members. Some are surprised and delighted at movements their child can perform in water. Parents are profoundly grateful to be able to hold **their fragile children and tenderly float them with confidence because of the water's viscosity.** They too, become relaxed and happy during the session.

Moving forward

Although the PPAP has been enthusiastically received at GMCH since 2006, critically important **questions remain unanswered for parents. These include: “What happens to my child after s/he ‘ages out’?” “What programs exist in the community that will help assure my child's quality of life?”**

In attempting to address these concerns, we were unable to locate any aquatic programs **specifically oriented toward the needs of young adults who have “aged out” of the pediatric** palliative care system in Bay Area counties. Sheila and her colleague, Linda Dold, an experienced palliative aquatic practitioner, have committed to starting an outpatient palliative aquatic program, *Palliative Aquatics for Pediatrics, Adolescents and Young Adults* (PAPAYA). Sheila and Linda plan to collaborate with parents to define and develop an aquatic program specifically tailored to the needs of medically-fragile adolescents and young adults living in our communities. We plan to include pediatric patients in this program as well. As of this writing,



we have secured use of a pool located in Contra Costa County. Our next step is to meet with interested parents and families. We envision this project as a collaborative effort that includes patients and their families, health care practitioners, aquatic practitioners with health care experience, and philanthropic entities. We welcome input and ideas from our colleagues. We plan to initiate this project toward the end of 2019.

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END-OF-LIFE DOULAS AS AN ESSENTIAL LAYER OF SUPPORT FOR CHILDREN AND FAMILIES

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“It’s amazing what you do,” a 16-year-old young woman with a brain tumor told me upon learning that I’m an end-of-life doula. **“I can’t imagine anyone would be interested in my story and what I’m experiencing.”**

“Why not?” I asked.

“Because it’s too hard for people. No one wants to hear about a girl dying from a brain tumor. No one wants to hear about her family and how devastating it is for everyone when no one can say what they really want to.”

“What if it didn’t have to be too hard?” I offered, focusing in on the pain this struggle was causing her. **“What if you could say exactly what needed saying?”**

She paused a moment in contemplation, mustering the courage to give voice to something it seemed she had been wrangling with awhile.

“I would tell my mom that it’s time to stop.” She took a deep breath and continued, **“I would tell her that I’m not afraid and even though I don’t want to go, it’s OK. She and my dad will be OK. My friends will be OK.”** She paused a moment more before adding, **“I will be OK.”**

It is a basic human need to feel heard, to know that we matter, and to **know that we’re not alone**. When you are a child experiencing life-limiting illness and all that that involves—among other things, navigating the chaos of family disruption; painful and confusing procedures and treatments; competing wants and needs from parents, caregivers, medical personnel; and the desire to just be a normal kid going to school and hanging out with friends—this is especially so.

For the parents of these children, there is the added layer of having these same basic human needs, and choosing to put them on a shelf in an effort to fulfill them for their child, for other children in the family, and not to mention, for their spouse. All the while finding their way, making unthinkable decisions, and trying to stay soulfully engaged while more or less having to make it up as they go along.

There is no guidebook for having a child with life-threatening illness; neither is there one for losing a child. Throughout the process of illness, however long endured, it is challenging to stay clear and remain close to what matters. It is difficult to ask for what is most important with so many competing priorities. It is almost impossible to remember that there is more to life than navigating the illness, the diagnosis, and the prognosis itself. And when death comes, life as we know it threatens to grind to a halt.

Families need as much support as possible.



We're so accustomed in Western culture to try and do things—especially the hardest things—ourselves. Most of us are woefully ill-equipped to ask for support, much less to open our heart to receive the help we need.

And it doesn't help that most of our support systems have difficulty sustaining the presence and impartiality required to tend to the uncertain foundation this seemingly unnavigable terrain is laid out upon. This uncertain and unknowable landscape is not a place that most of us are **willing or able to settle into when the circumstances of our lives don't directly require it of us**, leaving families feeling unworthy, unheard, and alone.

End-of-life doulas are equipped to provide this continuous, independent presence to support the child experiencing illness and facing end of life, and the family as a whole. They act as a trusted partner outside of the confines of the medical system and frequently changing medical teams to advocate for and honor the unique needs of the family, and every member of that family, as well.

With no agenda to fix, to change, or to make things different than they are, an end-of-life doula can support a family in their discernment process, in having difficult conversations, in navigating family dynamics, and ensuring that everyone has a voice. Being an impartial outsider, yet a trusted support, an end-of-life doula is able to make connections and see what someone closer in may miss, gently creating space for the opportunity to be consciously engaged with what is happening for everyone.

End-of-life doulas keep an eye towards possibility, circling back to what is most important to aid the family in staying close to the ways they can live fully, connected with each other as much as is possible and desired, in whatever choices are being navigated and made. They assist in preparing for big shifts and changes in the event that treatments become less effective and can support engaging with hospice services much sooner than is typical. And in partnership with the hospice care team, can invite opportunities for education and normalizing conversation about what to expect as end of life draws nearer.

More than anything, an end-of-life **doula creates space for the family's processing, reminding** them that they are more than a diagnosis, helping them create a life day-by-day that reflects and honors this. Through creating legacy projects and preparing an end-of-life vigil plan, which captures the desires of the child and the family about how to make the final days and hours most meaningful, opportunities arise to fully engage with the process of what is unfolding, inviting healing experiences for everyone involved, within themselves, and in relationship with one another.

Together, an end-of-life doula walks alongside a child and his or her family, allowing for **everyone's voice to be heard, honoring each person's unique experience, and weaving the story** of each individual within the larger context of the family story. The sense of belonging this engenders reminds them that they deserve to be heard, that their experience matters, and that they are not alone.

The depth of the doula-child/family relationship assists a family in inhabiting what is happening, not in an effort to alter it, but to be with each other more fully in it. There is relief and resiliency in this connection. I have experienced it time and time again with my clients and their loved ones when we were able to invite others into their circle of support because we had created and fostered a calm, open, and peaceful presence to rally others to help navigate the uncharted waters.



This close guidance and systemic support is especially important when it is a child that is dying. At the bedside of an actively dying child, parents need the opportunity to simply be parents; to be unwavering in their focus as they do the most difficult work of their lives in ushering their child on against their wishes. And the child who is dying needs the permission to know that everyone will be okay, and that they can follow their natural process into death. The presence of an end-of-life doula alleviates the pressures upon parents to be everything to everyone in such a scenario, while holding the dying child and the whole of the family in calm, comforting confidence at the same time. They may do this by:

- Creating sacred space for the child and those closest to that child who have been invited to the bedside to be uninterrupted by watching over what is happening, taking care of details, logistics, and answering nonessential questions and concerns
- Providing ample opportunity for loved ones to take breaks, have a meal, get some rest; reminding them that self-care is crucial to their ability to be meaningfully present for their child, assuring them they will be sent for if anything changes
- Cultivating an atmosphere that is calm and peaceful, regardless of what arises
- Including siblings and other children present of all ages, welcoming them to remain connected and engaged, as much as desired
- Keeping a spirit of lightness and childlike wonder surrounding the deep significance of the life that is ending—inviting the sharing of stories, telling favorite jokes, reading special books, playing meaningful music, etc.
- Encouraging and modeling continued contact and communication with the dying child even when they are experiencing an altered state of consciousness (coma, delirium, etc.)
- Normalizing the end-of-life process, educating those present on physical changes occurring as things progress, moment by moment, gathering those not in the room when death becomes imminent
- Prompting the possibility of ritual to honor the process leading up to and following physical death
- Reminding all members of the circle of support throughout the process that everything is unfolding naturally and that their child knows (as we all know) how to do this—both how to die, and how to care for our dying.

End-of-life doulas can also play a special role beyond the death of a child by:

- Participating in the planning and carrying out of a funeral/celebration of life, suggesting **opportunities and rituals to create a unique gathering that reflects the child's life and** how the family wishes to remember that child
- Reprocessing the death story with the family some days or weeks later, creating the opportunity for further healing and engagement with the loss as they recount the **experience and everyone's part in it**
- Assuring the family has the resources and connections they need in coping with their grief and loss, especially when other family members, community members, friends, and loved ones return to life as usual.

It is my belief that we each have a soul-knowing about how to die, how to care for our dying, and how to come together to make this as gentle and enlivening a process as possible for everyone fortunate enough to be a part of it. At its most basic, an end-of-life doula acts as a guide to this inner knowing, creating space and opportunity to engage with life in the face of death, and

tending to our most basic needs in the process—to **know that we and what’s happening to us matters, to trust we are heard, and to remember we’re not alone.**

With my support, the beautiful 16-year-old young woman who was so wise about the trajectory her own life **was taking, and so concerned for her family’s response to it, found the courage to** have that difficult conversation with her mother. While I was not with them when she passed, I heard that she died only a few weeks after they talked, grateful to have given voice to her **knowing and desires, to have been heard, and allowed to go on her own terms. It wasn’t easy;** and it was a good death.

When we are supported in this way, we are empowered and strengthened through our adversity, and our resilience and capacity to grieve consciously increases. The act of dying has so much to teach us, whether we are the one dying, or are simply witness to it. We grow, we change, we evolve as our experiences press in upon us, the pressure of which creates preciousness and light within, if we let it. It may break us—the grief that comes from loss always does in one way or another. And then we rebuild, on a foundation different than the one that we started with; hopefully stronger. Working with an end-of-life doula helps in remembering that while death is guaranteed, life does indeed go on. And that we can do what feels impossible, especially when we do it together.

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MEDICAL MARIJUANA IN PEDIATRIC PALLIATIVE CARE

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Medical Marijuana, also called medical cannabis, is the hot new thing. Families are trialing medical marijuana for a number of purposes. In my practice alone, I have been asked about its use for acute pain, chronic pain, chemotherapy-induced nausea, dystonia, insomnia, anxiety, seizures, anti-neoplastic therapy, muscle soreness, aggressive behavior, self-injurious behavior, irritability, autonomic dysfunction, and discomfort related to autonomic dysfunction. And those **are just the queries that I can recall while writing this. I'm sure there have been others.**

So what do we know about medical marijuana for pediatric palliative care in 2019 and what do we not know? And when a family asks about medical marijuana for one of the many symptoms or diseases listed above, what can we tell them about evidence and efficacy?

Let's start by defining a few terms so we are all speaking the same language:

Cannabis: a plant that serves as a source of food, fiber, oil and medicine. Genus, species: *cannabis, sativa L.*

Marijuana: a dried mixture of the leaves and flowers of the cannabis plant.

Medical marijuana/medical cannabis: cannabis obtained from state-run or state-approved dispensaries, typically used for medicinal purposes.

Cannabinoids: A diverse class of chemical compounds that act on cannabinoid receptors in the body. Cannabinoids can be manufactured (synthetic), naturally occurring in plants (phytocannabinoids), and naturally occurring in our bodies (endocannabinoids).

Hemp: strains of the cannabis plant that are often grown for the fibrous materials found in stalks. It contains minimal amounts of the psychoactive phytocannabinoids and is legal to grow in the United States thanks to the Agricultural Act of 2014 and the recently signed Hemp Farming Act of 2018 which changed it to an agricultural commodity and not a controlled substance.

Cannabidiol: A chemical compound found in the cannabis plant. Also the name of a medication newly approved by the Food and Drug Administration (FDA) for treatment of epilepsy in patients with Dravet Syndrome and Lennox-Gastaut Syndrome—the first FDA-approved botanical extract from the cannabis plant. To avoid confusion, when talking about the medication, we will utilize the brand name of this medication: Epidiolex®.

CBD: an abbreviation for the chemical compound cannabidiol. This can be extracted from cannabis but also from hemp. CBD from hemp is legal and is sold widely, including but not limited to at vape shops, tobacco shops, coffee shops¹, and even ice cream parlors².

THC: An abbreviation for Tetrahydrocannabinol, the primary psychoactive phytocannabinoid.



Recreational marijuana: marijuana obtained from sources outside of state-run/state-approved dispensaries, typically used for recreational purposes. Of note, anecdotally, there are people who do not have access to state-sanctioned dispensaries who are using recreational marijuana for medicinal purposes, and vice-versa, using medical marijuana for recreational purposes. The source of the product does not automatically indicate its use.

With our definitions clear, let's look at the evidence. In the United States, we currently have three FDA-approved medications that have evidence backing their use: dronabinol, nabilone, and newly on the market, cannabidiol (Epidiolex):

Medication	Synthetic cannabinoid or botanical extract?	FDA approved indication(s)	FDA approved for pediatric use?
Dronabinol (Marinol®)	Synthetic	Chemotherapy-induced nausea and vomiting, HIV-related anorexia	No, though commonly used off-label in pediatrics
Nabilone (Cesamet®)	Synthetic	Chemotherapy-induced nausea and vomiting	No
Cannabidiol (Epidiolex®)	Botanical extract	Epilepsy for patients with Dravet Syndrome and Lennox-Gastaut Syndrome	Yes

These medications are the best studied of all cannabis products and cannabis-like compounds (cannabinoids), and the package insert for Epidiolex® represents the best source of information regarding side effects of CBD. All other commercially available products, including all products from medical marijuana dispensaries, are untested, unstudied, and unknown. To be clear—unstudied is not synonymous with ineffective. These products might work for their intended uses. We just do not know yet. The science is lagging desperately behind the marketplace. A recently published systematic review of the pediatric literature shows that evidence is strongest for treatment of chemotherapy-induced nausea and vomiting with increasing evidence in pediatric epilepsy. All other uses, including spasticity, neuropathic pain, post-traumatic stress disorder and Tourette Syndrome, have insufficient evidence.³

So where does this leave pediatric palliative care patients, families and providers? At a crossroads not too dissimilar from all crossroads in PPC. Patients and families have a choice to

try something that may work but may not work; it may have side effects, or it may be well tolerated; it may be a waste of money, or it may be money well spent. And we as providers have a choice as to how to walk with our families on this journey.

If I declined to offer advice, suggestions, and recommendations for all but evidence-based therapies, I would quickly have nothing to say to PPC patients and families. For that reason, I am as open and honest about medical marijuana as I am about every other treatment in palliative care. There is a lot we do not know, but there are some things (beyond FDA-approved medications) that we do know. For example:

- **In a study of families who started medical marijuana to treat their child's epilepsy, 71% discontinued use within 1 year because of lack of efficacy⁴**
- Daily recreational marijuana users show a statistically significant decline in IQ from childhood to adulthood for those who start using before the age of 18 years old⁵
- The FDA warned recently over companies who were claiming their products cure or treat cancer⁶
- Medical marijuana is not regulated and not always safe⁷
- Medical marijuana can be expensive and is not covered by insurance

So, my advice?

- Counsel families appropriately—for most indications, medical marijuana and/or CBD has no evidence supporting its use. We know that recreational marijuana has deleterious effects on the developing brain. We do not yet know the effects of CBD alone. For this reason, prognosis matters.
- Follow your state law—if your state does not have a law in place for pediatric medical marijuana use, CBD from hemp or off-label use of FDA-approved cannabinoids will be the only options available to your patients. Clinicians prescribe FDA-approved medications. *We do not prescribe CBD or medical marijuana.* At best we oversee its use, counseling patients and families, and titrate other medications as indicated. At worst, we are unaware of what our patients are using.
- Start low, go slow—for patients and families who are interested in trialing medical marijuana or CBD for pain or symptom management, they should be instructed to start low and go slow with dose increases. Dosages vary by product, depending on the precise mix of phytocannabinoids in each product. However, I find the package insert for Epidiolex® to be a good guide for CBD dosage ranges that families can target.
- Titrate to effect—unlike FDA-approved medications where doses are carefully titrated by **medical providers, this “medication” is titrated by the family, often without any communication with the child's medical providers. For this reason, families should be instructed to stop increasing the dose once they reach the desired effect (i.e., resolution of nausea) or if side effects develop (see below).**
- Watch for sedation with concomitant benzodiazepine use.
- Watch for side-effects, especially in children who cannot tell us how the medication makes them feel—common side-effects of CBD include somnolence, decreased appetite, diarrhea, fatigue, malaise, and poor sleep.
- Avoid the up-sell—there are many products sold at medical marijuana dispensaries that are higher in price. Cannabidiol is highly lipophilic and easily absorbed enterally in the oil-based preparations commonly made for pediatric use. Topical creams and lotions may be unnecessarily expensive without increased efficacy. (Thanks, for the advice, Cousin Zach!)

The AAP “recognizes that marijuana may currently be an option for cannabinoid administration for children with life-limiting or severely debilitating conditions and for whom current therapies are inadequate” and “strongly supports research and development of pharmaceutical cannabinoids and supports a review of policies promoting research on the medical use of these compounds. The AAP recommends changing marijuana from a Drug Enforcement Administration schedule I to a schedule II drug to facilitate this research.”⁸ And I agree!

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GUIDING PARENTS TO MINDFULNESS: LOW TECH IN A HIGH-TECH ENVIRONMENT

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This article develops the concept that helping families find a mindful inner state may help them make the best decisions for their child. We have explored how a low-tech means of helping families, who are open to it, allows them to move towards mindfulness without training or extensive practice. At the outset, there are five things to know about mindfulness¹:

1. Our brain has two distinct modes:
 - One deals with the outside world
 - One deals with the inside world.... **the** mindful world
2. When your thinking goes up, your mindfulness goes down, and vice versa.
 - ***THIS IS WHERE OUR PATIENTS AND THEIR FAMILIES FIND THEMSELVES MUCH OF THE TIME....in the THINKING mode rather than mindful***
3. The Language of Your Inner World -- *It doesn't use words*
 - Communication comes in the form of body feelings, background emotions, unexpected aha moments, and gradual change.
4. The Landscape of Your Inner World -- **It's a quiet place. It's a place for self-reflection.**
 - (Some people get anxious when there is too much quiet)
 - *When you observe and then try to change something, it will take you out of the mindful (inner) mode and back into the outer mode.*
5. Mindfulness – **You don't have to learn anything new.**
 - *Humans are hard-wired to be mindful. You just need to practice. It is difficult to let go of all the inner talking, fears and doubts that occupy most of our thoughts and negative emotions. It's difficult to remember to be mindful.*

Achieving a calm state of mind to make the best decision and listen to one's own "inner wisdom" is difficult in the hospital setting. From an existential perspective, many families find themselves **victims of their child's disease. They can become immobilized through fear, anxiety, grief, confusion, and the very real threat of losing their child's life or well-being.** In such a mental state, it may be impossible to listen to one's own heart for guidance. Instead, families may only



hear the frantic inner dialog of their minds and emotions which obscure the subtler messages of the heart. The recent recognition of frequent PTSD symptoms in both families and patients who survive the ICU speaks powerfully to the stress and toxicity of the environment in which we care for patients.

A recent editorial entitled “Humanizing the Intensive Care Unit”² in the adult ICU setting highlights the need to actively rethink the environment we have created to provide high tech care to medically fragile human beings, aka patients (Table 1). I believe that in the world of pediatric medicine, we are far more responsive to the needs of our patients than in much of adult medicine, but we are far from perfect. We frequently **round outside the patient’s room because the throng of interdisciplinary team members would overwhelm the small space allotted for each patient.** The focus is usually more often on numbers and data from the **electronic medical record, getting the day’s progress note entered, and writing medical orders.** Teaching happens occasionally on work rounds but the crush of patients, the acuity, and the need to keep rounds under three hours drives much of the pace. Communication with the patient and family during rounds becomes a secondary priority. While most of us offer to have families listen in on rounds, there is limited time for in-depth explanations and discussion of **options.....because the work must go on. (Disclaimer: Even though I know better, I am no better when attending on the ICU, because there are so many chores that must be done to keep things moving.)**



The primary tools we use to work with families and most patients are our words, although many child life therapists are adept at using play and pictures to allow young children to express themselves. But, for most situations, we have family meetings to present information, we have social work and psychology visits to explore family goals and values. We ask our chaplains to visit and provide emotional and spiritual support through discussion and reading of scripture. The common thread in all of this work is the reliance on words. And, when language is a barrier we enlist the help of interpreters, although that is often an imperfect solution as our ability to nuance conversation through an interpreter is never as good as we can do in our own native tongue. Of course, families come in all varieties with greater and lesser capacity to express themselves or even recognize their fears and worries. Thus, verbally-based work is successful for some patients and families, is not effective for others, and leads to frustration for some.

Regardless of communication style, most people and families have what is commonly referred to as *unfinished business* that we attempt to address in preparing for death. Unfinished business may represent issues from this lifetime that patients have acquired and wrestled with without full resolution, or it may represent issues that one came into this lifetime with. Whether or not we believe in past lives or future lives, many adults recognize themes running through their lives. Such recurring themes offer opportunities for personal growth, just as illness and adversity offer opportunities for personal growth and the development of new insights. Therefore, part of life closure/completion is helping our patients identify those themes and complete whatever is unfinished.

One of the primary traits of human beings is the ability to communicate our thoughts and feelings through words, gestures, pictures, songs, melodies, and the like. When people are non-verbal (infants), neurologically impaired, or demented, they lose some aspects of the human

quality of communication. When they are unconscious, they are totally unable to communicate **effectively. If intact humans have unfinished business, then why don't we think that non-communicating individuals also have a need to finish their life's business before death ensues?** This problem has vexed me for many years: how best to help individuals complete their life work when they are non-verbal, comatose, or have advanced dementia.

As part of my sojourning in Northern California, I was fortunate to meet many gifted integrative medicine practitioners. Some were of the Hmong healing tradition³ that understands the human spirit differently than we do in Western societies. Others were from more of a Native American or South American variety of shamanic healers who, similar to the Hmong, saw life from an animistic² perspective and viewed the human spirit from a very different perspective than do our Western monotheistic theologies.^{4 5} What all of the trustworthy healers I met had in common was the recognition of the importance of supporting the human spirit and healing spiritual wounding prior to death. Their ability to perceive other dimensions of reality than we in the industrialized societies believe to be real was a remarkable experience for me to have. My goal in this article is not to **attempt to prove to the reader the indubitable experiences my patients'** families and I had with these practitioners, because that would take more finesse than I possess. But, as a very conventionally trained ICU and palliative care physician, I want to share an approach we have found helpful to families grappling with difficult decision making for their children, whether acutely ill in the ICU or referred for palliative care consultation. Some of this work is contained in a short videoclip.⁶ **Shakespeare said it best, when he wrote: "There are more things in heaven and earth, Horatio, Than are dreamt of in your philosophy."**⁷

The Case of XP:

XP was a little boy diagnosed at approximately 6 months of age with Gaucher Disease Type 2 (acute infantile neuronopathic Gaucher disease). He began losing milestones and ultimately had a tracheostomy and ventilator placed at about 10 months of age due to inability to tolerate extubation after a viral respiratory infection. His responsiveness diminished, and seizures became a prominent feature in his life. Prior to receiving the tracheostomy, the parents had been referred to me for palliative care consultation, but felt they were not ready to consider limitations of life support. Once the tracheostomy had been done, there were limited options for him other than hospital or home and his parents once again contacted me to request bringing **their son to a regional children's hospice that could handle his ventilator. I explained** that we could provide care for him, if the intention was to discontinue artificial life-sustaining therapies in a finite period of time, but that we could not provide care over an indefinite period of time. We discussed quality of life issues for their minimally responsive son, who continued to have intermittent seizures in spite of expert management of his anticonvulsants. But the family continued to be undecided about their ultimate goals of care, defaulting to the understandable position of sustaining his life artificially until they had more clarity as to what they wanted to do.

The child was hospitalized at a long-term care facility for technology-dependent children and the family spent as much time with him as possible over the following months. They were devoted to him, his personhood, and coming to the best possible decision for him given the **grave prognosis. His mother said, "I am afraid to end his life.....** his dad and I had struggled quite a bit with 'when to remove the ventilator'." They consulted with the local Catholic diocese,

² Animism (Meriam-Webster)- 1) a doctrine that the vital principle of organic development is immaterial spirit; 2) attribution of conscious life to objects in and phenomena of nature or to inanimate objects; 3) belief in the existence of spirits separable from bodies

the Catholic committee on bioethics, several Buddhist thought leaders, and read many papers about bioethics. The father undertook a Native American vision quest in his search for the best choice.

On a subsequent conversation with them, I asked whether they would be open to meeting one of the healers I had come to work with in my ICU practice in California. They agreed to meet her and began a relationship with her that has continued to the present as they continue to do their own healing work. The shamanic practitioner met with the family several times over the following weeks. She provided gentle drumming³ as a mindfulness technique, with minimal **verbal direction, to help the parents shift their ‘analysis paralysis’, into a more heart centered, calm state of knowing, insight and clarity.** The process was much the same as experienced with mindfulness-based stress reduction and meditation, which can lead to an inner place where the cacophonous inner dialog of our heads grows quiet and we become aware of ourselves without any words. In that inner, mindful space families may get new insights regarding the decisions which have been weighing on them in their normal state of being. The parents came to the decision to discontinue mechanical ventilation on a specific date they chose. Their son lived **peacefully for several more days, held in his parents’ arms, and surrounded by his family.**

After his death, his mother made several poignant comments about the process that allowed them to **make the difficult decision to allow his life to end.** She said, “Your work supported us in going deeper into ourselves, our hearts, and our connecting with (him). It was so important and what you offered was a very different and very welcome perspective in making a decision which, while in the medical context, was not purely medical. Your work empowered us to make the best decision for our family in a context that transformed us and our hearts to move forward. When I felt this in my heart I was able to really truly know what the right thing was to do and to have the **courage in my heart to let (him) go.**” **Parents bring their child’s life into this world and do not want to feel they are ending their child’s life by their decisions. Facilitating parents into a mindful state, where they can access their heart-centered clarity, is more effectively achieved through a non-verbal, mindful technique such as gentle drumming.**

Conclusion:

In helping families make difficult decisions for their children, we need to explore options beyond the conventional methods offered in our Western healthcare facilities. Verbal discourse only goes so far for many people and often falls short in connecting them with their true feelings, which likely originate from the heart rather than the brain. We have successfully incorporated age-old methods of helping numerous families and patients achieve a peaceful inner state of mindfulness. We cannot explain in Western scientific terms how such approaches work, but we have seen time and time again the effect of such approaches in the decisions families make and the sense of peace they achieve.



³ Drumming also appears to synchronize the lower areas of the brain (non-verbal) with the higher cortical regions (language and reasoning). This integration produces feelings of insight and certainty ⁸.

Table I (from reference ²)

<u>Dehumanizing behaviors:</u>	<u>Humanizing behaviors:</u>
<ul style="list-style-type: none"> • Loss of identity (and appearance) • Loss of ability to communicate • Loss of ability to advocate for one's self • Loss of family presence • Loss of control • Loss of respect • Loss of modesty/privacy • Purposeful shaming/mocking • Purposeful exploitation (e.g., for research) 	<ul style="list-style-type: none"> • Unrestricted family visitation • Knowing the patient as a person (nonmedical facts) • Physical touch (e.g., holding a hand) • Communicate with the patient (not just about or above the patient) • Common courtesy communication, especially to delirious/comatose patients (introduction, explanation of what is about to happen, permission to touch) • Attending promptly to patient needs • Individualizing communication modalities • Giving patients some locus of control of their environment • Using eyeglasses, hearing aids, dentures as feasible • Personal hygiene (hair care, oral care, etc.)

References:

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5. Carson C. *Spirited Medicine: Shamanism in Contemporary Healthcare*. Otter Bay Books; 2013.
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7. Shakespeare W. *Hamlet, Prince of Denmark*. [Hamlet Act 1, scene 5](#) Stratford on Avon in Jolly old England ~1599.
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ITEMS OF INTEREST

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

1. NHPCO Palliative Care Online Resources:

NHPCO has a variety of pediatric hospice and palliative care resources available at www.nhpc.org/pediatrics. Also, more palliative care resources are available at www.nhpc.org/palliativecare, including:

- Community –Based Palliative Care
- Legal and Regulatory Resources
- Webinars and Courses
- Plus more for NHPCO members

Palliative Care Programs and Professionals

Founded in 1978, National Hospice and Palliative Care Organization (NHPCO) is the **world's largest and most innovative national membership organization devoted** exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families. Join NHPCO Today!

[Individual Palliative Care Membership](#)

[Palliative Care Group Application](#) - Save by registering your entire team

2. Pediatric Hospice and Palliative Care Resources:

- CaringInfo, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. www.caringinfo.org
 - *When Your Child is in Pain*
 - *Talking With Your Child About His or Her Illness*
 - *Talking to Your Child's Doctor: When Your Child Has a Serious Illness*
 - *When a Child Dies: A Guide for Family and Friends*
 - *Helping Children Cope with the Loss of a Loved One*
- NHPCO's Palliative Care Resource Series includes pediatric palliative resources such as:
 - *Communication Between Parents and Health Care Professionals Enhances Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy*
 - *Consideration for Complex Pediatric Palliative Care Discharges*
 - *'Who You Gonna Call?' Men with Duchenne Muscular Dystrophy Discuss End-of-Life Planning*
 - *Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and Hospice Care*
 - *Nonpharmacological Pain Management for Children*
 - *Sibling Grief*
 - *Pediatric Pain Management Strategies*
 - *Communicating with a Child Experiencing the Death of a Loved One: Developmental Considerations*



3. Trends in Pediatric Palliative Care Research

Every month PedPalASCNET collects new pediatric palliative care research. For past lists visit [their blog](#), [browse in their library](#), or join the [Zotero group](#).

Commentary:

This month Dr. Lorna Fraser discusses palliative care for children with Cystic Fibrosis and how the discussion is complicated by the lack of clear definitions for supportive and palliative care

[View the New Citation List in their Library](#)

[View a PDF of the New Citation List](#)

Feature Article:

Friedman, D., Linnemann, R. W., Altstein, L. L., Georgiopoulos, A. M., Islam, S., Bach, K. T., St John, A., Fracchia, M. S., Neuringer, I., Lapey, A., Sicilian, L., Moskowitz, S. M., &Yonker, L. M. (2019). [Effects of a primary palliative care intervention on quality of life and mental health in cystic fibrosis](#). Pediatric Pulmonology.

[Click here for the Commentary](#)

4. Pediatric Hospice and Palliative Care Training:

- Upcoming 2019 Webinars provided by the Pediatric Care Coalition:
 - May 23:
Providing Spiritual Care with Pediatric Patients
Presenter: Rev. Travis C. Overbeck
 - June 20:
Ensuring Psychosocial Wellness in School and Community for the Seriously Ill Child
Presenter: Kathy Davis
 - July 18:
Care of Adolescents and Young Adults with Life-Threatening Illness
Presenter: Jenny Mack
 - September 19:
Pain Management for Children with Serious Illness in the Context of the Opioid Epidemic
Presenter: Stefan Friedrichsdorf
 - October 17:
An Expense Worth Expressing: The Role Of Expressive Arts in Pediatric Palliative Care
Presenter: Debra Lotstein
 - November 21:
Compatible with Life: Rethinking Care of Children with Trisomy 18
Presenter: Nicole Hahnlén & Deanna Deeter

- Pediatric Advisory Council members and E-Journal subscribers are invited to attend the Optum Annual Hospice Conference free of charge. We will waive the registration fee of \$99 so they you may experience first-hand this amazing pediatric hospice-specific education. Use the group code CHIPPS during registration.

The annual conference is June 13-14, in Charlotte, NC, at the Omni Charlotte Hotel. This two-day conference includes both a pediatric and adult clinical track, as well as keynote speakers, amazing meals and reception. Participants also receive a complimentary copy of choice of publication: *Palliative Care Consultant, 4th Edition* (Retail Price \$69.99); *Pediatric Palliative Care Consultant* (Retail Price \$69.99); or ***Wound Care at End of Life, 2nd Edition*** (Retail Price \$29.99)!

[CLICK HERE](#) for more information and to register.

5. [Subjects and Contributors for Future Issues of This E-Journal](#). For upcoming E-Journal issues, we plan to address issues related to Myth Busting. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at ctorkildson@mail.cho.org or christytork@gmail.com; or Ann Fitzsimons at ann@here4U.net. We will work with you!

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