August 2020

in this issue

Pediatric Hospice and Palliative Care Resource Guide

The Journal

of the Louisiana-Mississippi Hospice & Palliative Care Organization

The Future of Concurrent Pediatric Palliative Care

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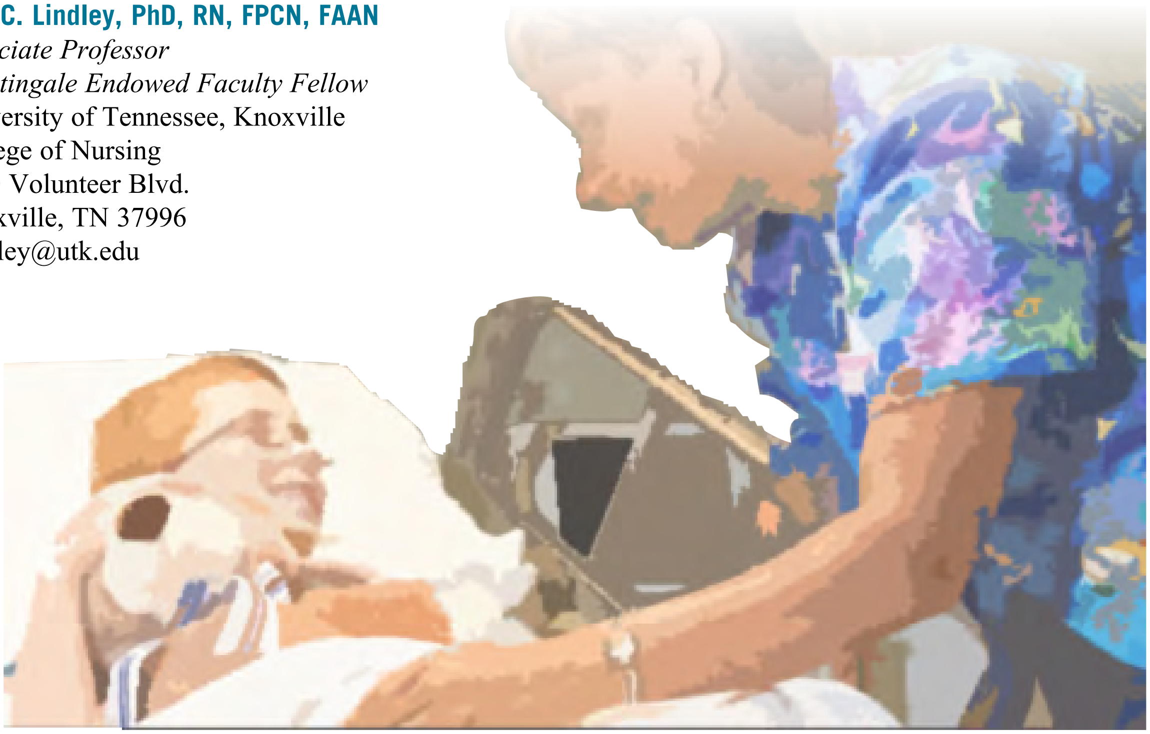

For this month's *Journal*, I was asked to give my opinion about what pediatric concurrent care might look like in a perfect world. As a pediatric hospice nurse scientist, I have a unique birds-eye view from my work that enables me to explore specialized pediatric end-of-life care and hear the concerns in the end-of-life community across multiple states. It is clear there is no perfect, but there is an emerging national profile of children enrolled in concurrent hospice care, which is hospice care provided at the same time as curative care. However, given our current state of COVID19 and health care crisis, I would modestly suggest that as we progress towards that perfect world, the addition of the letter "s" might move us in that direction. Under the current language from the Centers for Medicare & Medicaid Services (CMS), concurrent care is:

> A voluntary election to have payment made for hospice care for a child (as defined by the State) shall not constitute a waiver of any rights of the child to be provided with, or to have payment made under this title for, services that are related to the care of the child's condition for which a diagnosis of terminal illness has been made.

next month: THE INTERDISCIPLINARY GROUP

In this definition, concurrent care is confined to a single terminal illness diagnosis. For example, a child with cancer might continue to receive chemotherapy and radiation during their hospice admission. And yet, for those who care for these children know, children suffer from multiple terminal diagnoses. Our current research examining concurrent care among a national sample of Medicaid beneficiaries suggests that almost 40% of children in concurrent care have multiple terminal illness diagnoses. So, are they receiving care for one terminal illness or many? And which one is chosen and by whom? A perfect world might allow children to continue to receive curative care for all their terminal illnesses when they enroll in hospice care.

This may be wishing a bit beyond a perfect world, but what if we took that "s" and made it all diagnosed illnesses. In addition, to their terminal illness, we were able to cover the care for non-terminal conditions. Again, our work shows that a third of children entering hospice care have a mental and behavioral health diagnosis. The main conditions include ADHD, depression disorders, clinical anxiety, and behavioral problems. In the current environment, medications, therapies, and counseling all cease when children enter hospice care, even concurrent care. Do these mental and behavioral conditions convert to symptoms and become part of the pantheon of hospice-managed symptoms or do they go untreated at end of life? As a pediatric end-of-life community, we often discuss wholistic end-of-life care, but it would be amazing if by simply adding an "s" we improved child- and family -centered care for these little ones through concurrent care.

A perfect world might allow children to continue to receive curative care for all their terminal illnesses when they enroll in hospice care.

A Note from the Editor

The Future is Now!

When the Education Committee settled on this tag line for the July Conference, we never imagined how our world would change in such a short period of time.

The good news is that Pediatric Palliative Care is evolving rapidly and the future looks very bright! It's not an exaggeration to say that this August Journal would not be possible without the efforts of the forward-thinking Gulf States Pediatric Palliative Care Consortium. This talented, energetic group of professionals are shining a light on the importance of pediatric palliative care. They generously wrote informative articles and provided numerous resources that include toolkits, policies, bereavement resources, organizational resources, training and education opportunities. You will be amazed at what's available when you go to the Pediatric Palliative Care page on LMHPCO's website https://lmhpco.memberclicks.net/pediatric-palliative-care.

If anyone needs convincing that pediatric palliative care is critically important, please read and circulate to your staff and board members the powerful story of young Bella Bowman's journey. We can all create a space in our organizations for providing pediatric palliative care.

There is nothing I can say that is as impactful as the articles within this month's Pediatric Palliative Care Resource Guide. Read them, learn and imagine how we can do this better.

– Susan

We can all create a space in our organizations for providing pediatric palliative care.

Developing Outpatient Pediatric Palliative Care

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I have always been the ultimate "baby hog," the 8-year-old walking around with a 20- pound toddler on her hip. As one of the first grandchildren in my family and the oldest child in a blended family of six, I naturally fell into caring for the many kiddos who came after me. Subsequently, when it came time to choose my medical career path, I knew where my heart lied: pediatrics.

My interest in pediatric palliative care (PPC) began in the PICU during my third year of medical school. I came in one morning to find Emmy, a 16-year-old girl that had been transferred from an outside hospital in rural Louisiana. She had just attempted suicide by hanging. While meeting with the family to discuss the care plan, I kept thinking, "I will not cry. I will not cry. They need me to hold it together." We explained that their daughter had suffered an anoxic brain injury that lead to cerebral edema and ultimately, brain herniation. We discussed the process of declaring 'death by neurologic criteria'. We told them that they had done everything they could, that this was not their fault, and most importantly, that their daughter was not in pain. Emmy's family understood and appropriately began to grieve for Emmy. I left the hospital with a newfound sense of pride. I recognized the immense honor and responsibility of being a part of that experience. I helped a family get through the worst day of their lives. While the day was extremely hard and painful, I learned the value of putting the family's needs first and the extraordinary reward of compassionate communication and shared medical decision making.

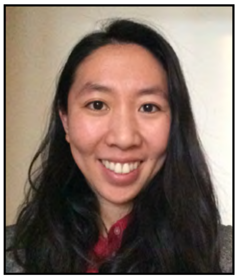
> …I learned the value of putting the family's needs first and the extraordinary reward of compassionate communication and shared medical decision making.

Whether a child is losing his or her life or a family is dealing with a new life-limiting or life-threatening diagnosis, PPC physicians have the honor of guiding them through the hardship. After suffering the loss of my young cousin to suicide, my family and I learned the importance in recognizing that people handle difficult situations and grief in their own way. This gave me a unique perspective when caring for Emmy that day, and I believe my own personal experiences of loss and death continue to permeate my daily practice today.

I am incredibly honored to now be caring for our deep south children and families dealing with serious illness. I was born and raised in New Orleans, LA and attended Tulane for both undergraduate and medical school. I then spent four years in Memphis, TN for my pediatric residency and hospice and palliative medicine fellowship at UTHSC. While training at Le Bonheur Children's Hospital and St. Jude Children's Research Hospital, I was able to learn from some of the most experienced PPC physicians in the world. I am now thrilled to be able to return to my hometown, join Dr. Alexis Morvant at Children's Hospital New Orleans (CHNOLA) and contribute to the growth of PPC in our beloved community. I look forward to developing outpatient PPC services here at CHNOLA and partnering with local hospice agencies to improve pediatric hospice care throughout LA and MS. Finally, I am also very passionate about bereavement. I treasure learning from bereaved parents' experiences throughout the course of their child's illness, the end of their child's life and throughout their bereavement.

improve health outcomes for our minority patients to achieve health equity

Implications of Implicit Bias in Pediatric Palliative Care



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Racism is a core social determinant of health which must be addressed to achieve health equity. It is well documented that racial and ethnic disparities in pediatrics exist and literature shows that implicit bias contributes to perpetuating inequalities.[1,3,6] Implicit bias is defined as "unconscious attitudes and beliefs that may influence behaviors such as nonverbal communication, physician perceptions and clinical assessments about patients, and decisions about patient management." [3] Implicit bias has been shown to significantly impact patient-provider interactions, treatment decisions, treatment adherence and patient health outcomes.[1]

Large scale studies have shown that most healthcare providers have pro-white and anti-Black implicit bias similar to what is seen in the general population. Various studies in adult populations have shown the effects of these biases in patient care however there is limited data assessing the direct effects of implicit bias in Pediatrics. Studies show that racial bias experiences are associated with negative psychological outcomes which can increase anxiety, depression, low self-esteem and behavioral problems in pediatric populations.[7] With continued experiences of racial biases there are increases in emotional and physiological stress in the body which can cause physical implications further exacerbating chronic illnesses.[7]

In one particular study looking at youth experiences with sickle cell disease (SCD), a population that many Palliative medicine physicians care for, participants were asked about their racial bias experiences and the impact on their care. They reported few instances of experiencing racial bias in clinical settings, but did report multiple instances in the community and school settings.[7] They also reported experiencing more instances of racial bias from authority figures rather than peers, which was concerning due to inherent power differentials.[7] Additionally, the study found a significant range of negative emotions including sadness and anger in response to racial bias events indicating youth understanding and conceptualization of racial bias as a stressor.[7] It was also noted that Black parents of children with SCD perceived that racial bias impacted the quality of healthcare their children received, and were more likely to report this negatively impacted their child's care compared to Black parents of children with asthma.[7] This is of particular interest since perceived racial biases also increase barriers to healthcare which adds to the complexities of transitioning kids to adult medicine.[7] This makes an already sensitive and vulnerable time period for children with chronic illnesses even more stressful when adding in racial biases. Overall, more research needs to be done to study racial bias experiences in youth, especially those with chronic illnesses, to understand how these encounters affect health outcomes in a population that will need to continuously interact with the healthcare system throughout their lifespan.

While further data driven efforts will help the medical community understand the profound impact of racism and implicit bias on patient experiences and subsequently on health outcomes, there are steps that clinicians can take to intervene and break down these biases. Three actionable steps are outlined below, and further resources and strategies are available through the American Academy of Pediatrics (AAP) policy statement on the Impact of Racism on Child and Adolescent Health.[6]

1. Understanding our own implicit biases as individuals and how they influence medical care. Harvard University has created a free and validated tool known as the Implicit Association Test (IAT) which is used to measure implicit bias and gauge its effects on individual biases.[3]

2. Providing a welcoming clinical environment for patients and families including training clinical and office staff on culturally humble care.

3. Ensuring that clinicians openly share medical knowledge and thought processes and prioritize shared medical decision making with patients and families.

It is clear that racism in the form of implicit bias impacts Pediatric patients. As Palliative Medicine and Hospice professionals, we need to make changes in our practice to better advocate and improve health outcomes for our minority patients to achieve health equity.

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Take a Pause for the Cause

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As palliative care and hospice practitioners, we adapt ourselves to meet patient's needs. We take on the challenge wholeheartedly and without consideration of ourselves. We know how to be present with people at their worst. We know how to celebrate the smallest victories and we value time spent with people in a way that is different from the rest of the world. The essence of what we do is not taught or learned, innately it lies within each of us. Serving the pediatric population deserves its own recognition due to the heightened level of intensity and the myriad of complexities that go along with the expected death of a young person.

Compassion fatigue is a real threat to palliative care and hospice providers.

The connections that we make with people require intimacy, authenticity, trust, confidence and a sense of our true self. Self-reflection becomes a priority when we do this work, in order to keep our own chaos out of the homes of our patients. The constant intensity can be extremely exhausting emotionally, physically, and spiritually. I have found ways to balance this.

When I first began my career in hospice (20 years ago), a wise nurse told me that I will need to develop a self-care routine to sustain myself or the consequences would be burnout. She explained how burnout negatively affects the ability to be empathetic, which is key in the role that I had just taken on. Compassion fatigue is a real threat to palliative care and hospice providers. Small daily consistent practices help us to keep ourselves in balance. We can take what we know and break it into small practices throughout the day, rather than it being something we dreadfully have to do at the end of an emotionally exhausting day. For example, we can practice the use of ritual and imagination and we can temper the way that we breathe. We can examine what is happening within ourselves and in that awareness, we can "take a pause for the cause." We do such a great job of using our empathy for the sake of others and often times, we forget that we owe ourselves a bit of the care that we share with those we serve. Allowing yourself a moment to recharge, reset, or reboot throughout the day can have a great impact on the overall care you provide. It can re-energize your mind, body and spirit. One positive change can create space for other positive opportunities to show up.

SHORT and SWEET SELF-CARE TRICKS TO WEAVE INTO YOUR DAY:

- 3 minute breathing exercise: Set your clock for 3 minutes. Relax your brow, your jaw, and allow your shoulders to drop away from your ears. Allow yourself to notice your breath. Make the inhales and exhales full, expand your ribs. Place your hands on your ribs at your sides and keep your breath even and slow paced. Do not force breath in or out. Allow yourself to notice the cool sensation of the breath entering your body and the warmth of the exhale. Keep it slow and work to extend the exhale longer than the inhale. Notice what comes up for you like physical sensations, irritation, discomfort a sense of urgency to be done. But don't stop until your alarm rings. Use your senses to keep you in the present. Can you feel your toes? Can you feel the contact of your body on the surface in which you are seated? Are your hands clenched? Is your jaw clenched? Relax. Sometimes, I envision that I am taking in what serves me well on my inhale and releasing that which does not serve me well on my exhale. It's only 3 minutes. You got this!
- Blowing bubbles: I keep a bottle of cheap bubbles around and use it to help me focus on something lighthearted. This is a great way to spark joy (Who doesn't like bubbles?) My neighbors know that they can expect bubbles from my house at any random moment. Don't be afraid to have fun! Laughter IS the best medicine!
- A journey of the senses: Look around you. What do you see? Notice things that you would not normally tune in to. Notice the clouds, notice the color of the sky, the foliage, flowers, and colors of the leaves. Notice any sounds you hear like birds, wind in the trees, traffic flow or lawn care equipment. Notice your physical body. Do you feel your toes? Are your hands

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PEDIATRIC PALLIATIVE CARE FROM A LEARNER'S PERSPECTIVE

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In New Orleans, our culture dictates that “family” extends beyond those related to us by blood, and we have become accustomed to relying on this large community for support. However, in the setting of Covid-19, our communities have begun to shrink; and in the hospital, the effect has been notable. Patient rooms that have often been flooded with family, related and not, now seem quiet. The hospital can be a confusing and overwhelming place: unfamiliar and complicated diagnoses, sudden and under-explained changes in care plans, unexpected deteriorations with new problems, and, most difficult of all, coming to terms with a poor prognosis. Life outside the hospital requires constant adjustments to this “new normal,” and it can be even more challenging to adjust to the ever-changing environment inside of one. However, throughout this time, our palliative care team has made an impact in providing that consistent support system for our families. The team becomes part of the family’s narrative, knowing and understanding our patients beyond their medical diagnoses, and ensuring that the care plan matches the families’ goals. And so, I remain hopeful that despite the shrinking number of family members within the hospital walls, our palliative care team is becoming that community, and those hospital rooms don’t seem quite so quiet.

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During my first year of medical school, I was flooded with information on anatomy, enzymatic pathways, disease presentations, and much more. While the information was exciting to learn, sometimes it could be difficult to see things past the immediate assessments of information. This summer, I reached out to Dr. Morvant and the Pelican Krewe team at Children’s Hospital New Orleans. I joined morning rounds through Zoom, read through patient charts, and heard insights from these pediatric palliative care providers. I was quickly touched by how real and unique these patients were. They were no longer just textbook conditions to memorize, but instead that rare congenital abnormality I had studied suddenly had a name, a family, a spirituality, and goals.

Dr. Morvant would sometimes use the word “reframe” to refer to conversations she had when meeting patients and their families. She would reframe concepts about their diagnosis and treatment to ensure better understanding and align plans with their goals. As I reflect on my summer, I find that this team has helped me reframe my medical training in a positive way. Learning from this team has allowed me to reframe the symptom presentations and disease pathways I currently study into actual people that I will one day provide care to in the future. Now, as I continue to study, I will picture patients with hopes, fears, pain, and laughter. I have always valued learning about individuals and their unique experiences, and I believe this summer has helped me lay the groundwork for becoming a better physician and treating the whole patient.

Cause

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relaxed? Notice what your body is making contact with like the clothes you are wearing, the seat that you are sitting on, and whether you feel any tension anywhere.

- Use your imagination: Invite joy through imagination
- Password mantras: We type in so many passwords. Make them work for you. I use positive thoughts and abbreviate them to meet the password criteria. Example: I might take a phrase like “gratitude is key for happiness” and use GkH100% for a password. Each time I type the password, I say the phrase to myself as a reminder.
- Decompress: If you run at high speed all day or if your daily experience is intense, allow yourself to decompress. Hot baths are great to decompress!
- DO MORE OF WHAT MAKES YOU FEEL GOOD: Tune in to what makes you feel at ease and do that. We must balance the effort of our daily roles with ease. Balance is truly the secret to sustaining our passion in our roles.

Adapting Hospice and Palliative Care for Pediatric Patients

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When most people think about hospice and palliative care, they do not think about children, but children deserve access to the holistic benefit of hospice and palliative care just as their adult counterparts do. Hospice for children is unique; pediatric patients continuing aggressive treatment may elect hospice in addition to their existing treatment. This care model, called Concurrent Care, allows pediatric patients to receive expert pain and symptom management from an interdisciplinary care team wherever they call home without sacrificing treatment options.

Caring for pediatric patients, though similar to caring for adult hospice and palliative care patients, requires some unique considerations. It is important to remember that, while your patient is your priority, parents and siblings of the patient will also be deeply involved in the child's care. Interdisciplinary team members must not only address the physical, emotional, spiritual, and psychosocial needs of the child, but of their siblings as well. The care team will need to involve families in care planning as they wish and keep an open line of communication as goals of care for children may be quite different from those of an adult hospice patient. Caring for pediatric patients can be challenging; it is okay to express some level of nervousness to the patient's family and ask questions along the way. Parents are often the experts when it comes to the care of their own child. It is also important to collaborate with the child's pediatrician, or if the child does not have one, consult with another pediatrician when planning care.

Logistically, providing pain and symptom management for pediatric patients is different as well. Equipment is often specialized, and medications are often non-formulary. Pain assessments might occur differently depending on the age of the patient. Self-reported pain scales will likely need to be modified to the child's language abilities to work effectively. In infants, pain detection will be behavioral or physiologic, so it is important to collaborate with the family to best detect any changes in their child's baseline. When administering treatment for pediatric pain, medications should be titrated accordingly—weigh your patients and adjust their medications according to their recorded weight.

Some hospices offer specialized pediatric hospice programs, like Heart of Hospice's Kids at Heart. If you think a pediatric patient might be eligible for hospice or palliative services, it is best to contact an experienced provider for more information. Most providers will offer free assessments to determine if either hospice or palliative care is the right fit. To schedule a free consultation or learn more, Heart of Hospice is always available at: 1.844.404.0411.

YOUR SOURCE FOR PEDIATIRC PALLIATIVE CARE INFORMATION

LMHPCO'S website provides a plethora of resources including toolkits, policies, pediatric bereavement resources, organizational resources, training and education opportunities. PEDIATRIC PALLIATIVE CARE RESOURCES

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Click here to see the progress being made by the consortium beginning with the summit in 2019. GULF STATES PEDIATRIC PALLIATIVE CARE CONSORTIUM

If you want to go fast, go alone. If you want to go far, go together.

-African proverb

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The future of pediatric hospice and palliative care is collaboration. Our goal for the children of the gulf south is that every child gets the right care, every time. This is a big vision. Multiple sectors must work together to achieve this shared goal. Fortunately, the interdisciplinary, integrated teamwork needed is exactly what we are trained to do.

We started a pilot pediatric palliative care program in Baton Rouge in 2011. We had a very energetic band of clinicians who passionately took on palliative care as a "hobby." We performed consults for patients with a range of conditions, we completed a needs assessment with pediatricians and subspecialists, we hosted monthly committee meetings to provide education and build enthusiasm, we received a grant to improve pain management, we got specialized training and then provided training for others. We did all of this in our spare time as everyone involved had a full-time position in another area. The value was clear, and we had a lot of energy. Unfortunately, we lacked the institutional support and network of collaborators needed to get this initiative going. Now the program in New Orleans is having better success. We hope that the gulf south community can build off this momentum and work toward our global goal.

Ensuring high quality care for every child requires us to match our services to the goals of the family while focusing our resources on the services most likely to accomplish these goals. There is so much that goes into this and the barriers are many, but integrated palliative care is certainly part of the solution. Imagine if every child diagnosed with a serious condition could have a meeting with an interdisciplinary palliative care team. Imagine if every family could choose the location of death without worry that if they chose to go home there will not be enough support. Imagine if every provider had excellent communication skills so that patients always achieved good understanding of their condition allowing them to make informed decisions about their care.

If our vision is for every child to receive high quality palliative care, then we must ensure that we are acting at multiple levels to make this vision a reality. The palliative care report card https://reportcard.capc.org/ describes the status of palliative care in each state and gives concrete recommendations for moving forward. Appropriately acting on the elements in this report are fundamental to our success. We can also look at other states across the US and adapt successful programs (such as telemedicine networks or state funded pediatric palliative care programs) to meet the needs of our patients.

What does the future of pediatric palliative care for the gulf south look like? Advocacy at all levels is essential. Investment from institutions, payors, and governments will drive the initial programs. These programs will demonstrate value and patient/family demand will drive further expansion. Together, we will go far.

WHAT CAN I DO TODAY?

- **Have your program join the Palliative Care Quality Collaborative https://palliativequality.org/ and provide data that can be aggregated to fuel our advocacy efforts.**
- **Collect patient stories and develop a narrative history of the value of pediatric palliative care.**
- **Identify patients/families that will make good advocates and develop a patient/family advisory council.**

“Palliative Care”-What is that?

On January 1, 2011; our daughter Bella Bowman was diagnosed with an ependymoma brain tumor. On December 23, 2011; she died from a radiation necrosis that occurred shortly after she received radiation treatments post her tumor resection surgery.

During this almost 12-month journey we had many ups and downs. When we were introduced to Palliative Care it seemed like a huge weight had been lifted off our shoulders. We did not lose sight of doing what was best for Bella’s health; but we did begin to look at a bigger picture and changed our views to start doing things that Bella would want.

Bella’s last 10 days of life were probably the most memorable days for her and our family. We have so many precious memories during her time of Palliative Care. Things like; her first communion, watching the newly released Alvin and the Chipmunks movie as a family, visits from Disney princesses and smiles from our daughter. To this day, our decision to accept Palliative Care for our child was quite special to us because precious memories we created.

These are a few things that will never be forgotten:

- Barbie dolls given to Bella every day.
- A personal visit from Miss Louisiana and honoring Bella as a princess.
- Transforming Bella’s hospital room, the way she would have wanted it. Filling the room with Christmas decorations.
- Visits from Santa Clause, Cinderella, pet therapy dogs and her very own 6-week old kitten.
- Quiet time for only mom, dad, and Bella.
- Medical staff treating Bella as if these were not her last days.

Some of the most important things we feel that should not go overlooked are:

- Plenty of space (patient room, plus one) for family to feel at home.
- Medical staff close by, if needed.
- Live each day to its fullest and as if it was the last day with your child.
  - Video/photo all memories and moments created with the family. Record your child as much as possible. We did not have this but today, wish we would have done so, primarily for our younger daughter.

We will always say, ‘the last 10 days of Bella’s life, were probably the most heroic days she lived!’

Bella Bowman FOUNDATION

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The foundation’s mission is to create and support Research initiatives for pediatric brain cancer, fund new and continuous Education, and offer Comfort Care to others. The foundation focuses on several areas; however, Trey and Kim have a passion for the Comfort Care aspect, as Bella’s last days of life were so very special.

"How can we do this better?"

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> ***Once the infant is born, clinical assessments are confirmed immediately post-delivery and the family is given the opportunity to adjust the plan with the clinicians.***

Woman's Hospital, Baton Rouge, **Mission Statement:** To improve the health of women and infants; may include Palliative Care…

"How can we do this better?" the question asked repeatedly between staff while finding themselves working over the bed of numerous tiny patients with a life-limiting diagnosis or at the end of their life because of prematurity or illness. After much discussion between Neonatologists, Perinatologists, members of the leadership team, nurses and social services, a Perinatal/Neonatal Palliative Care Team was formed. Seven core members of this team attended PCLC-Pediatric Training at Children's Hospitals and Clinics of Minnesota where they were able to learn from a team whose experience and processes were setting the gold standard for pediatric palliative care.

Once a life-limiting diagnosis of an infant is determined during a pregnancy, a Maternal Fetal Medicine physician refers the patient for counseling. A certified palliative care social worker and RN along with a Neonatologist meet with the family and formulate a palliative care plan based on information from the most current diagnostics, and consultant assessments. The goal of the perinatal/neonatal palliative care program is to provide seamless care to our families through various phases of pregnancy, labor and delivery, postpartum and neonatal care. The comprehensive palliative care plan is disseminated to all team members in all specialties and disciplines involved in the patient's care. Clinicians provide care through the birth continuum to ensure that all family wishes regarding the infant are carried out. Once the infant is born, clinical assessments are confirmed immediately post-delivery and the family is given the opportunity to adjust the plan with the clinicians. The family can choose to transfer the infant from the delivery room to the NICU or have the infant remain with the mother in her room. Occasionally our NICU patients are discharged to their home with Hospice. If our families desire in-house Hospice, we convert the NICU room into a more home-like environment. We place a baby bed, donated by a local baby store, in the patient's room and invite the family to personalize it by bringing in their own baby bedding, mobile, pictures, etc. . . . Our visitation policy is waived, lights are dimmed, soft music is offered, and the parents lead the way for the care of their infant with the support from the NICU physicians, staff, social services and the chaplain.

Our team has expanded in members and meets biweekly to discuss a master list of high risk pregnant patients who will receive coordinated care for their infants. We also review current palliative care patients who may have started out with a life limiting diagnosis or who have developed one over time. A debrief is held on cases to identify what went well and what we can improve on. The mission of our palliative care program is "providing interdisciplinary, compassionate, comforting care for babies with life-limiting illness and their families". Simply said, our goal is for these precious infants to live as long as possible as well as possible. Our journey is far from over but we continue with the knowledge that Perinatal/Neonatal palliative care is necessary and when done well, beautiful.

NHPCO
Leading Person-Centered Care

Pediatric E-Journal

Care Throughout the Dying Process

August 2020, Issue #60

The 60th issue of the Pediatric E-Journal is now available! This issue is focused on care throughout the dying process in connection with pediatric palliative and end-of-life care. The collection of articles covers many aspects of this care, including supporting parents and addressing their questions, memory and meaning making with children, and addressing pediatric patients' understanding of and desire to engage on the topic of death and trajectory of their illness.

Also, be sure to catch the Items of Interest section at the end of the E-Journal for news and resources related to pediatric hospice and palliative care.

A few highlights from this issue:
Changing the Narrative of Pediatric Death and Dying: The Story of a Bereaved Parent Serving as an End-of-Life Doula and Home Funeral Guide
Artificial Nutrition at the End of a Child's Life
Advance Care Planning with a Teenager: Empowering their Voice and Choice at the End of Life
Silenced Suffering in Second Trimester Pregnancy Termination
Read these and other great articles now. Available to view online or to download.

NHPCO
National Hospice and Palliative Care Organization

Just 10 minutes of your time can help improve the care given to seriously ill children. Whether or not you currently provide pediatric care, your input will help shape the future of pediatric palliative and hospice care.

The objective of the National Pediatric Survey is to collect data from each hospice and palliative care provider across the United States to understand the current state of access to care, understand barriers to access, and identify opportunities to eliminate barriers to improve access..

One person should respond for each individual hospice/palliative care location and be knowledgeable of the pediatric offerings that the location provides (if any). If your organization is part of a larger health care provider with multiple locations, please make sure your answers reflect the offerings available at your hospice/palliative care location only.

Please note that you must complete the survey in one sitting, as you don›t have the ability to save your progress.

Whether you have a full pediatric program, can provide services for the occasional pediatric patient, or are not currently providing pediatric services, we want to hear from you!

Complete the survey here.

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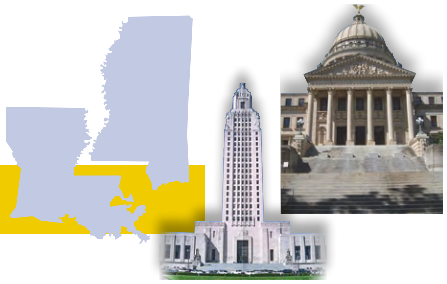
Alliance NEWS



LOUISIANA UPDATE

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MISSISSIPPI UPDATE

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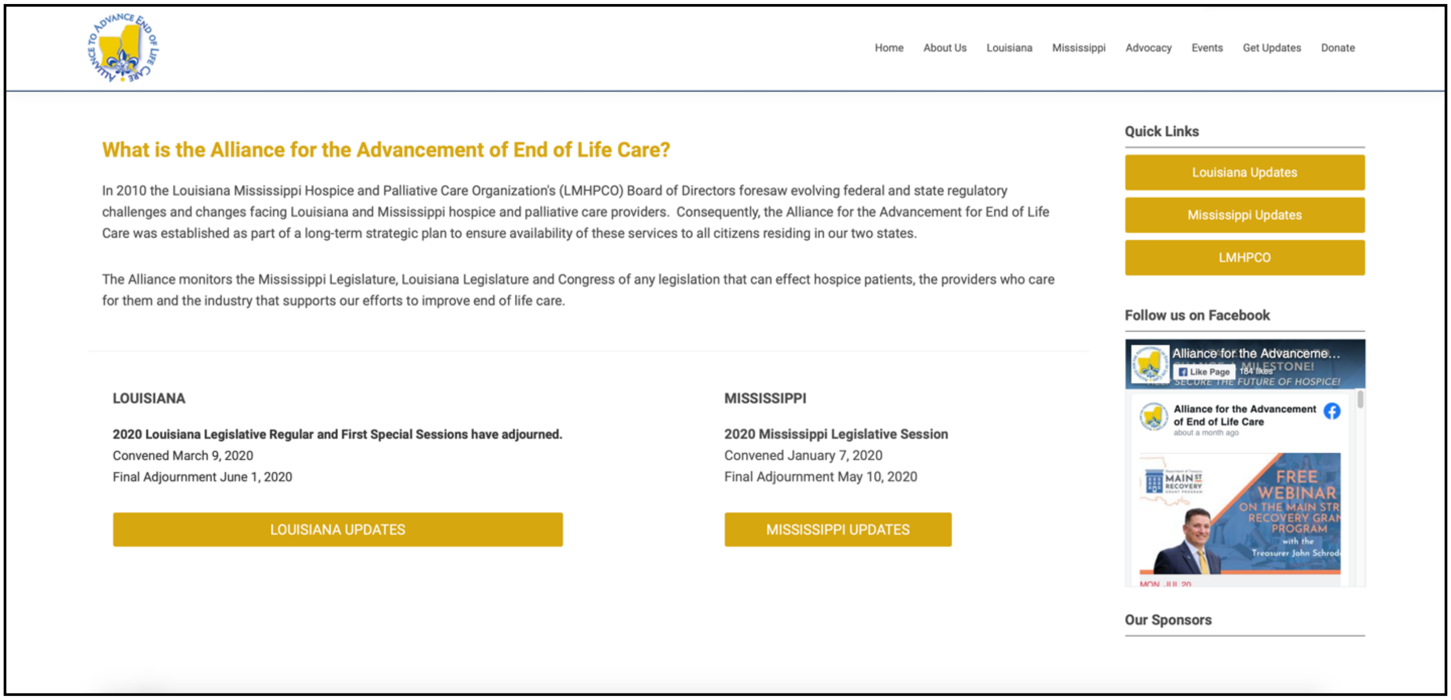
Check out our NEW website!
www.allianceforendoflifecare.org

We have new website with updated information and links! The site will be updated weekly with new information. There are sections for state regulatory information, legislative updates and events (hopefully we can have some again in the near future). There is also information on current hot topics such as opioids, COVID-19 and state advisory councils.

You can even login to LMHPCO account straight from our website!



What is the Alliance for the Advancement of End of Life Care?

In 2010 the Louisiana Mississippi Hospice and Palliative Care Organization's (LMHPCO) Board of Directors foresaw evolving federal and state regulatory challenges and changes facing Louisiana and Mississippi hospice and palliative care providers. Consequently, the Alliance for the Advancement for End of Life Care was established as part of a long-term strategic plan to ensure availability of these services to all citizens residing in our two states.

The Alliance monitors the Mississippi Legislature, Louisiana Legislature and Congress of any legislation that can effect hospice patients, the providers who care for them and the industry that supports our efforts to improve end of life care.

LOUISIANA

2020 Louisiana Legislative Regular and First Special Sessions have adjourned.
Convened March 9, 2020
Final Adjournment June 1, 2020

MISSISSIPPI

2020 Mississippi Legislative Session
Convened January 7, 2020
Final Adjournment May 10, 2020

LOUISIANA~MISSISSIPPI BOARD OF DIRECTORS

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LMHPCO is a 501(c)3 educational corporation, networking hospice agencies for the purpose of improving end-of-life care and services for everyone living in Louisiana and Mississippi through research, professional education, public awareness and advocacy.

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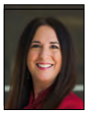

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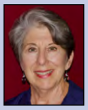

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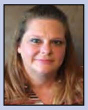

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Building alliances that ensure the best care for patients and families facing end-of-life.

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