Welcome to the 49th issue of the ChiPPS E-Journal. This edition of our E-Journal offers a collection of articles that explore selected issues related to perinatal and neonatal palliative/hospice care of children and their families. We recognize that offering care at these early points in life is an important aspect of pediatric palliative/hospice services. As well, we appreciate that such care is offered in many different ways. A single issue on this subject will not do full justice to this subject area. Still, we were a bit surprised to receive a larger-than-ordinary collection of contributions for this issue. Consequently, we hope that the articles in this issue will spur increased awareness and discussion of these subjects. We welcome communications from anyone who has more to offer on these subjects.

This E-Journal is produced by ChiPPS (the Children’s Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO’s E-Journal Work Group, co-chaired by Christy Torkildson and Ann Fitzsimons. Archived issues of this publication are available at www.nhpco.org/pediatrics.

Comments about the activities of ChiPPS, its E-Journal Work Group, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Please contact Christy Torkildson at christytork@gmail.com or Ann Fitzsimons at ann@here4U.net

Produced by the ChiPPS E-Journal Work Group

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Going through the Grits
Scott Newport
In this article, our resident poet and essayist meditates on sharpening a knife to remove its imperfections by going from the coarsest grit sandpaper to the finest. At the same time, he reflects on the death of his son Evan and on the struggles of another father with a child with a life-threatening condition (who eventually died).

A Cradling Song
Rev. John Bell
When a colleague and his wife suffered the death of their daughter shortly after birth, the father reported that this loss was compounded by the lack of any text which encapsulated their experience and feelings when it came to the funeral. Rev. Bell composed the text of a poem that drew on this couple’s experience. Here are the five stanzas of that poem.

Liliana’s Story
Laura Wotta, Liliana’s mother
This is the first of three articles in which parents describe unexpected complications in pregnancy leading to challenges, losses, and a child’s death. Here a scan in a second pregnancy led to a diagnosis of Trisomy 18. Liliana was stillborn, but good advance planning enabled the entire family to spend a precious day in the hospital with her. As her mother writes, “Although it was a difficult situation, it turned out to be such a wonderful day and a wonderful way to honor her…. Perinatal hospice allowed us to spend all our time loving her and making memories when she was born, instead of making difficult decisions.”

A Story of HoPE
By Charity’s Mom and Dad
In their third pregnancy, these parents were confronted with an unexpected diagnosis of Alobar Holoprosencephaly (HPE) and three fateful words, “Incompatible with life.” They chose not to end the pregnancy and received support from EDMARC Hospice for Children in writing a birthing plan and looking to the future after Charity’s birth. In fact, Charity did not immediately die as expected. She lived for nearly three years and her parents now write that “perhaps the biggest thing we have learned is that in so many ways, Charity is a very typical child. She refuses to listen to adults and do what they expect her to do.”

Finding a Way when There Seemed to be no Way: The Journey to Palliative Care for Our Son, Silas
Courtney Fields Connelly, M.Ed., Silas’ mother
For this family, a second pregnancy led to a diagnosis of Hypoplastic Left Heart Syndrome (HLHS). They write, “We struggled in making a decision from the impossible choices in front of us.” After discussing surgery with their pediatric cardiologist, they chose not to begin “a battle that would never result in him getting better. A battle that would never lead to a cure.” Working with a neonatologist who had extensive experience in pediatric palliative care, they developed a program of comfort care for Silas that led to an amazingly beautiful yet tragically short 56 hours in the arms of those who loved him deeply and that became the catalyst for “the only hospital-based perinatal palliative care program in the state of Oklahoma.”

Caring for Families Experiencing Perinatal Loss
Mellisa Reeves
This is the first of two articles in which the authors present guidance for professionals in caring for families experiencing perinatal loss. In this case, after the stillbirth of the author’s second son at full term, she decided that her work would be “telling the stories of motherhood in all their forms and variations.” Here under four main headings, she offers “some strategies I believe can make all the difference in allowing providers to offer the most emotionally accessible and thoughtful care possible.” She concludes that, while some aspects of this model of care may be outside the abilities of a standard health care...
professional or practice, any person can allow intuition and compassion to guide the care they provide to women and families experiencing loss."

**Pearls from Parents**  
**Sue Steen, RN, MS**  
The author is an experienced perinatal nurse navigator who asked bereaved parents to share the things that they would like others to know about their journey and also the pearls of wisdom they learned along the way. The short, pithy comments that result confirm her conclusion that, "Bereaved parents have remarkable insights and we can learn from them. We are blessed to be able to take this journey with them. May we continue to learn from them in hopes of being better prepared to help."

**Perinatal Palliative Care: Two Decades of Exponential Growth**  
**Amy Kuebelbeck**  
The author of this article is editor and founder of www.perinatalhospice.org. She is also uniquely placed to review the developmental of perinatal palliative/hospice care since its first appearance 20 years ago. As she writes, "the growth of this practical and compassionate model of care has been exponential." With some 300 programs now in existence around the world, barriers and concerns remain, but the examples cited here indicate that the model of care is reaching a critical mass.

**A Brief Overview of Perinatal Palliative Care Research and Practice**  
**Elizabeth Levang, PhD, Tammy Ruiz Ziegler, RN, CPLC, & Rana Limbo, PhD, RN, CPLC, FAAN**  
This article seeks to provide the reader with examples of current evidence-based research, suggestions for a clinical practice framework, a case study, and rationales to support the need for competencies. The authors conclude that, "With increasing interest in policy, research, planning, parent satisfaction, decision making, program development, and caregiver and parental competencies, PPC is seen as the opportunity to be present as families care valiantly for their most vulnerable family member with love, grace, and generosity of spirit."

**The Devil is in the Details: Implementing an Integrated Perinatal Palliative Care Process**  
**Suzanne S. Toce, MD**  
Although this article notes that, "Developing a perinatal palliative care process that is continuous and coordinated across sites and providers is challenging, especially if there are multiple organizations involved," it uses two case examples to offer a detailed list of some aspects to consider in developing and implementing a successful program. The conclusion is that, "Successful implementation certainly takes more time and effort than is expected! However, the effort results in an improved outcome for the newborn, the family, and the health care providers."

**Suncoast Hospice | Empath Health Perinatal Loss Service**  
**Susan Finkelstein, RN, MAS, and Stacy Orloff, Ed.D., LCSW, ACHP-SW**  
These authors describe the history of an early perinatal loss program, the challenges it faced as the needs of its community changed and the program expanded, lessons learned, and future strategic plans. An example illustrates how the program responded when asked to assist families in need of some additional support when there was an option of termination of the pregnancy due to severe fetal congenital anomalies.

**Neonatal Pharmacokinetic Considerations**  
**Melissa Hunt, Pharm.D.**  
This article explains why pharmacokinetic considerations are challenging in neonates and offers detailed guidance for effective, patient-specific management of symptoms in neonates.

**The Post-Mortem Conference Following the Death of a Fetus or Neonate: A Step Closer to Closure**  
**Marilyn A. Fisher, M.D., M.S.**  
Exploring the many variables that may be involved in a post-mortem conference following the death of a
fetus or neonate is a great strength of this article. No less important is its conclusion: "The post-mortem conference, and the relationship formed between the health care professionals and the grieving family, provide us the opportunity: to assist the family in understanding the cause of their baby's death, to understand what the baby might have been experiencing, to assist the family in seeking appropriate supports, and to plan for the future. Often, the relationship between the family and the health care professionals endures over time and fosters further healing and closure for the family."

Perinatal Palliative Care/Hospice-Related Resources
Compiled by Ann Fitzsimons, BS, MBA
This helpful article compiles lists of: websites for parents, and separately, for care providers and professionals; toolkits; sample birth plans; a link to a perinatal photography resource; books for parents; books for siblings; and relevant DVDs.

Readers' Corners
Suzanne S. Toce, MD
In two Readers' Corners articles, Dr. Toce provides brief summaries of articles from professional journals on "Palliative care in the neonatal unit: Neonatal nursing staff perceptions of facilitators and barriers in a regional tertiary nursery" and on "Communicating prognosis with parents of critically ill infants: Direct observation of clinician behaviors." The summary of each article includes its background, methods, results, and conclusions. More importantly for readers, Dr. Toce explains: Who is the audience for this information? What is special about this information? And where and how can I apply this information?

Trends in Pediatric Palliative Care Citation List and Commentary, 2017, #10
From the PedPalASCNET
Here we are given a commentary on one featured article, plus the latest monthly list of recent publications in the field of pediatric palliative care. The ChiPPS E-Journal Work Group includes this bibliographical list as an additional service to readers who can see previous citation lists and expert commentaries by visiting the PedPalASCNET blog at http://pediatricpalliative.com/research-blog/

ADDITIONAL NOTES

ChiPPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.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, ChiPPS and its E-Journal Work Group, 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 ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the ChiPPS Web page at www.nhpco.org/pediatrics for previous issues of this E-Journal, additional materials, and other resources of interest.
It was another day at a renovation project on the fourth floor of an office building. Glancing at my iPhone, I noticed that my buddy Dave had called a couple of times. Now, coming down a stepladder for what seemed like the hundredth time, I saw his name pop up again. This time I set down my hammer and found a quiet place.

"Hey Scott, ol' buddy, I got a request," Dave said. "Last week at hunting camp, a friend of mine was impressed with my restored knife. As we were sitting around the campfire, I told him that you're kind of a blacksmith, and that you refurbish knives. I wonder if you could fix up his, too. He lent it to me, and I want to return it to him as a Christmas present."

After work, I picked up the knife from Dave and headed home. There I walked into my workshop, a few yards from my house, set the knife on my bench, and then went up to the house.

Stepping inside, I received a text: "Hey Scott, it's Ryan and I'm not sure what to do. Hospice wants to talk with us on Monday."

Ryan is a young guy referred to me about a year ago by Children's Special Health Care Services here in Michigan; I often mentor dads and families with children who have a terminal illness.

Earlier in the day, Ryan had texted me that his younger son had been readmitted to the pediatric intensive-care unit and was struggling to breathe.

I'd texted back that I would be praying for him, and that we could catch up by phone in the morning.

"The conversations at the hospital have been scary today," he'd replied, "and what a way to spend a Friday."

Standing there, at the top of the stairs, I said a prayer for him. Then I walked back out to the shop, sat down at my bench and examined the knife.

It was old, but of good quality; the leather sheath was broken in but intact, and the dull blade was rusty. Gingerly rotating the blade within my fingers, I could tell that it had been sharpened before, but only on one side.

With the flip of a switch, I started up my grinder and touched the blade to the sanding belt. Steadily, I worked my way through a series of belts, from the coarsest-grit sandpaper to the finest--a process known as "going through the grits."

Time passed. As the clock ticked past six, I kept right on. The smooth rasp of grit against steel and the sight of the sparks bouncing off the surface felt almost magical. I found the whole process soothing--especially now.

You see, this week was the anniversary of my own son's death. He died seven years ago, the day after Thanksgiving, at age seven.

After finishing the grinding process, I paused to inspect the blade through my bench magnifier. Assorted divots and heavy scratches still scarred the steel. To achieve a perfect polish, I'd have to go back over those blemishes.
So I carried out the grinding process once more, working my way through the coarse 120-grit and 150-grit sandpapers and finishing with superfine 400-grit.

Again, I peered through the magnifier. The imperfections were still there. As I headed over to grab a fresh sanding belt, Ryan texted me again: "Sounds good, we can talk tomorrow."

Something about this stopped me in my tracks.

*It might not be a good idea to go through the grits again,* I thought. *If I keep trying to get the knife perfect, there'll be nothing left. I mean, who wants a knife with only half a blade?*

Checking out the blade again under the magnifier's illuminated glass, I felt my thoughts turning to Ryan and his son. Quickly, before I could let myself go there, I grabbed a piece of softened sandpaper and started to refine the blade by hand.

Holding the knife under the magnifier, I also saw my hands, with their own grooves and dings from a hard day's work.

I knew that the finish paper couldn't remove the knife's deepest scars; but the polishing would give the whole blade a mirror finish, something I thought its owner might appreciate.

Awakening this morning, I rolled over to check my phone and see if Ryan had tried to contact me.

Lying there, I tried to figure out what I could say to him today. I never want to tell families that everything will be okay, or try to take away their grief. I tell them that I'm just there to listen and to help them navigate the journey of living with a sick child.

I also started to think about the knife. *If I grind it anymore, I'll destroy it.*

An idea came to me: *Maybe I can tell Ryan about the knife, and how it was made by a blacksmith, years ago. Maybe we can talk about the original creator's dream for the blade. Maybe it was a Christmas gift for someone--a gift that's been passed down to its present-day owner. With all the wear and tear on this knife, there's no doubt that it holds a mountain of stories within its core.*

I thought about my boy, Evan, and about Ryan's son, Kaleb. *In a way, they might be a bit like that imperfect steel,* I reflected. *I know the doctors don't want to keep trying interventions that may take Ryan's son's life. Maybe I can talk to him about how some things are better not fixed, and that maybe it's okay to just polish them up a bit. Man, I just don't know--but there's something there, I feel it. Maybe I shouldn't say "better not fixed...."

I was asking God for the right words. *Please, Lord, show me the way.*

I know that, for me, it's the memories that keep me going. Even though my Evan was also not perfect and had numerous deep scratches and divots, the memory of his glowing face is a perfect fit for the sheath in my own life--one I carry with me every day. The experience of living with a very sick child forges a deeper appreciation for life, an enduring spirit of hope that I can pass down to my family and the ones I serve. It's never easy to talk about a child's impending death, but maybe the reflections I've received today will one day help those whose hands I hold through the journey of not being able to take out all the scratches.

Yeah, scratches stink, don't they? But without them, there would be no proof of how we lived. And, thank the Lord (the original blacksmith), He doesn't use a magnifier.

Now, in the heart of the Christmas season, I pray that my reflections today can be a gift for Ryan--one that we both can share. And maybe, just maybe, I will share this story with Dave and his hunting buddy. I'm sure that they have a few things in their lives that can't be fixed, either.
Don't we all.

About the author:

Scott Newport is a carpenter by trade and has been in the remodeling business for nearly forty years. He volunteers with the Patient and Family Centered Care Advisory Council of CS Mott Children’s Hospital, in Ann Arbor, Michigan, serving regionally and nationally as an advocate for families with sick children. “My biggest passion is family mentoring, and I have a special interest in supporting dads. I always know I’ve made a connection when I get an email that reads, ‘Hey Scott, are you going to be up at the hospital this weekend?’ I believe that until we make a personal connection with a family, it’s almost impossible to have those important and often difficult discussions.” His stories can be found in the *Chicken Soup for the Soul* anthologies, and he is regular contributor to the *ChiPPS E-Journal* published by the National Hospice and Palliative Care Organization.

The preceding story was originally published on Friday, December 30, 2016, in *Pulse--Voices from the heart of medicine*, an electronic journal from the Albert Einstein College of Medicine. It is reprinted here by permission. The following is an additional reflection from Scott.

...  

I learned recently from Matt, the nurse who originally referred Ryan to me, that Ryan's son, Kaleb, had died a couple of weeks back. When Matt wrote to tell me about this death, I wrote back to him to say the following,

→Yes, Matt, I was informed of Kaleb's death. Over the months since we became connected, the family and I have had many conversations. I was at the funeral on Sunday. At the end of the service the dad got up to speak. His last words were to repeat the, ‘Warrior Mentality.’"

Warriors know how to take on affliction  
Warriors may get knocked down but they always get back up  
Warriors know the greater the battle the greater the reward and  
Warriors never go into battle alone

→Yea, I wrote that when Evan was alive and will often send that battle cry to families. I guess the dad thought it had meaning because of his gesture of reading it at his precious son's funeral."

→I love the last line, ‘Warriors never go into battle alone.’ Yes, Matt, without your kindness and compassion of bringing Ryan and me together, that would not have happened."

In the final hours of Ryan son's life, he called again. →Make sure your other son, Owen, knows what's going on,” I said. →Maybe it would be cool to take a picture of both boy's toes together.”

I then said, →remember when Evan died, my son and I carried Evan out of our home and placed him in the mortuary guy’s van.” The dad told me later they had also done that.

Anyway, Matt, I will not leave my families. We had a talk via text yesterday about grief and we are already building new bridges, bridges he will not cross alone.

Your buddy (The bridge builder), Scott

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At a meeting of the International Work Group on Death, Dying, and Bereavement, in Dunblane, Scotland, in November, 2016, Rev. John Bell gave a presentation on “Death and Dying in the Celtic Tradition.” He supported that presentation with a handout containing numerous examples of prayers, poems, and songs. One of the poems struck me as particularly appropriate for readers of this E-Journal. Accordingly, after a bit of time I asked permission to report the story that is the background to the following poem and to reprint its lyrics here in the hope that they might be of some consolation to others who have encountered the loss of a child at or close to birth.

Rev. Bell kindly refreshed my memory of the background story that he had told in Dunblane and recommended to its publisher that we be allowed to reprint it here. That permission was promptly granted without charge on the understandable requirement that we accompany the following lyrics with this acknowledgement: Words & Music (Tune: ‘Jennifer’) John L. Bell, copyright © 1996 WGRG, c/o Iona Community, Glasgow, Scotland. www.wildgoose.scot. GIA Publications Inc., exclusive North American Agent, 7404 South Mason Avenue, Chicago, IL 60638, USA. International Copyright Secured. All Rights Reserved. Reproduced by permission.

So the background to the following lyrics is, as Rev. Bell reported: Some years ago I met a young minister who, with his wife, had sustained the tragedy of the loss of their child at birth. The couple had been advised after a first scan that the baby was deformed and had been offered a termination, which they declined.

After six months, and following best medical practice, they were advised that the trauma of birth would most probably be sufficient to end the child’s life. They then decided to have her by Caesarean section. She entered into life, was cradled in their arms, baptized, and died within twenty minutes.

The young man said that whatever grief they had at losing their child, it was compounded by the lack of any text which encapsulated their experience and feelings when it came to the funeral.

I was very touched by the honesty expressed and later noted the salient parts of this couple’s story. Theirs was an experience which I, as a single man who is not a father, knew nothing about. Later I wrote the text of a poem, the verses of which draw largely on the couple’s experience. There was no intention of it being more widely disseminated, but sometime later they asked if it could be made available in the hospital where their child was born for other parents experiencing the same loss. Later a request was made for a tune to enable the song to be sung at the annual service of remembering for parents who have experienced a peri-natal death.

It is not a song which a congregation could sing. It is much better as a poem which can be read. To enable that, I composed a few chords which can be played on piano or organ as the text is read.

Here then is “A CRADLING SONG” (©1996 WGRG, c/o Iona Community, Glasgow G5 9JP)

1. We cannot care for you the way we wanted.  
   or cradle you or listen for your cry;  
   but, separated as we are by silence,  
   love will not die.

2. We cannot watch you growing into childhood 
   nor find a new uniqueness every day;  
   but special as you would have been among us,
you still will stay.

3. We cannot know the pain or the potential which passing years would summon or reveal; but for that true fulfilment Jesus promised we hope and feel.

4. So through the mess of anger, grief and tiredness, through tensions which are not yet reconciled, we give to God the worship of our sorrow and our dear child.

5. Lord, in your arms, which cradle all creation, we rest and place our baby beyond death, believing that she now, alive in heaven, breathes with your breath.
There is often so much naiveté when embarking on a pregnancy journey. Especially after previously experiencing a normal, healthy pregnancy and having a healthy baby. We were embarking on that naïve journey with our second pregnancy. Everything seemed to be going exactly as it should be in the first 20 weeks of pregnancy. And, looking back on it, I'm glad those 20 weeks went so smoothly and provided so much happiness. At the turn of 20 weeks, things drastically changed for our family.

We went into our 20-week ultrasound with no expectations. We figured everything would be fine and we'd head home with some nice ultrasound pictures. Of course, that isn't exactly how it went. We went home with a few ultrasound pictures, but also knowing the sonographers couldn't get a good view of the four heart chambers. And then an additional call shortly after we arrived home with another update, that they thought our baby potentially had an omphalocele—an abdominal wall defect where intestines, liver, or other organs stick outside of the belly. We were informed that we would be set up to go see a perinatologist and have another ultrasound performed. Throughout the next few days, I was still in that naïve state, assuming this was just a little bump in the road and everything would be okay. I even tried to postpone the appointment for a day because it didn't work with my schedule as well. But they told me they were fitting me in and it was important that I kept the appointment for that day, so I obliged.

I never could have been prepared for what we were about to hear at that appointment. After the ultrasound, we met with the perinatologist, and she listed off to us all the other things they found this time, and her suspicion that our baby had Trisomy 18. We elected to do an amniocentesis, which confirmed her suspicions. Over the next few weeks and after many other appointments, it was evident that if our baby made it to delivery, she might not make it through labor, and if she did make it through labor, she might not live long. Yet there were no guarantees for anything.

We were so blessed to have the support and guidance of so many wonderful staff and caregivers to guide us along the way and help us think about and make those tough decisions. As we were nearing our induction date, we had all our plans in place. We discussed what interventions we did and did not want if she was born alive but needed some assistance? What would we do if she didn't make it through labor, would we have a funeral? There were so many things to think about, to plan, to decide, more than we could have ever imagined.

We were so blessed to have the support and guidance of so many wonderful staff and caregivers to guide us along the way and help us think about and make those tough decisions. As we were nearing our induction date, we had all our plans in place. We discussed what interventions we did and did not want if she was born alive. We met with the home care and hospice nurses to discuss what we could and would do if she was born alive and was able to come home with us. We talked to a child life specialist to understand how best to explain the situation to our almost 2-year-old son. We made the decision on
which funeral home we would work with whenever the need would arise. We discussed all the memory making we wanted to do. It felt like, for a situation with such uncertainty, we were as ready as we could be for all of it.

Our sweet daughter, Liliana, made her debut at 36 weeks gestation. Although it was our goal with induction to try for a live birth, it wasn’t in her plans for it to go that way. Liliana was stillborn, but the love we all had for her was still abundant. We were blessed with spending the day in the hospital with her, taking hundreds of pictures with the help of Now I Lay Me Down To Sleep, and introducing her to her brother, grandparents, aunts, uncles, and cousins. She was constantly held the entire day. We got to baptize her, give her a bath, make hand and footprint molds, and do all the memory making we would have if she would have been born alive. Although it was a difficult situation, it turned out to be such a wonderful day and a wonderful way to honor her. We felt extremely fortunate to have such wonderful staff to support us and guide us along the way.

We found it so important to be provided with the appropriate diagnosis and given the necessary information to allow us to make the best decisions for our family. We were given the support and resources from the beginning and given the freedom to utilize as much or as little as we wanted. Although every family will have a different experience and have different wants and needs, I think it is so important to provide them with the appropriate information about their situation and inform them of the support available so they can make the best decisions. Even with that being said, I would encourage caregivers to empower families to be involved in their child’s birth and death as much as possible.

Perinatal hospice allowed us to do most of our birth planning and medical decision making prior to Liliana’s birth, which allowed us to spend all our time loving her and making memories when she was born, instead of making difficult decisions. We cherish every moment we got to spend with her and have so many beautiful memories with her. The pictures we have are priceless, and allow us to share her memory with all our friends and family forever.

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A Story of HoPE
Charity's Mom and Dad

--Incompatible with life." Those are the three words which set us on an amazing and miraculous journey.

Really, the story begins a little before those words. In the fall of 2014, we were on our way into another pregnancy and couldn't have been happier. Being "seasoned parents," which was really just a nice way of saying over 35, the doctors wanted to spend a little more time discussing family histories so we could know better what to be prepared for. We scheduled the appointment in the morning, and the entire family attended, with the idea that dad would continue to work afterwards, while mom and the two children could continue on with their day. The blood work had already come back fine, and a quick interview with a genetics counselor confirmed that we were low risk for everything. We spent most of the time chatting about life while eight-year-old Andrew and two-year-old Morgan entertained the group. Finally the big moment arrived, an opportunity for the children to see the first glimpse of their 20-week new sibling via ultrasound. The technician was quiet and focused on the business at hand while we made observations and pointed to hands, feet, and facial features. The technician finished up and we waited while she went out to get the doctor.

When the doctor arrived the atmosphere definitely changed as observations and measurements were made. No one was chatting. It was obvious; something was not quite right. We took Andrew outside to watch TV while we tried to wrap our minds around what was happening. The doctor said some words, gave a diagnosis, and then said the three fateful words, "--incompatible with life." They offered to just "take care of things" right then. Instead, we opted to go back to the genetics counselor's office where she wrote down the word "holoprosencephaly." She attempted to explain it, but I'm not sure we were listening. We gathered our family together, explained to our son that we didn't know what was going to happen, and went home.

The next weeks included more ultrasounds, tests, and various explanations on the difficulties facing our child. It included an appointment with a children's neurologist where we were handed a copy of the same Wikipedia article we had already googled on our own. We were given the official diagnosis that our unborn baby had Alobar Holoprosencephaly (HPE).

What we knew is that Holoprosencephaly (HPE) is a condition where the brain does not fully divide into two hemispheres. It can range from mild (Lobar) to moderate (Semilobar) to severe (Alobar). Most babies diagnosed with HPE do not make it to birth. Alobar HPE usually results in a lack of nose, merged eyes, and other severe developments. And what is a doctor visit without statistics? According to the Carter Centers for Brain Research in Holoprosencephaly and Related Malformations, "It is estimated that HPE affects between 1 in 5,000-10,000 live births. Since many pregnancies with a fetus diagnosed with HPE end in miscarriage, the frequency of HPE among all pregnancies may be as high as 1 in 200-250. Current studies indicate that only 3% of all fetuses with HPE survive to delivery and the vast majority of these infants do not survive past the first six months of life."

For our family, choosing to end the pregnancy was never an option. Instead, we chose to allow God and nature to continue our unborn child's life, realizing we would most likely never have the opportunity to meet before a premature end. We discussed continuing the pregnancy with our regular OB who agreed to continue providing care for us throughout the pregnancy.

Knowing the challenges we were facing, we were referred to EDMARC Hospice for Children, in Portsmouth, Virginia, for support. And at the time, we did not fully realize the amount of support we needed, or fully appreciate the gift we had just been given. EDMARC listened to our diagnosis and asked us how they could help. As we approached the ninth month of a pregnancy (that wasn't supposed to be), we asked for help writing a birthing plan and developing plans to enjoy what few precious moments we
may be granted with our child.

On January 11, 2015 at 4:19 AM, Charity was born at Chesapeake Regional Medical Center. The staff understood and supported our desire to keep care as simple as possible and allowed us to just hold our new daughter. Friends rushed Andrew and Morgan to the hospital so they could meet their sister and spend a few minutes with her while she was still with us. There was a general calm as we waited for the inevitable. Everyone did what was expected; everyone except Charity.

The next couple of hours were spent taking pictures and talking. Then there were questions about feeding, suddenly, hours turned to days. We took many pictures in the nursery. She had many visitors. She was baptized. Andrew read her bedtime stories while Morgan proclaimed that she “loves her baby sister” and asked “can we keep her?” with an innocence only a three-year old can. We celebrated her 1 and 2 week birthdays. Before we knew it, the staff was asking us about car seats and home plans. We suddenly found ourselves as unprepared as though we were first time parents. At just over two weeks old, Charity was discharged home where EDMARC met us, ready to provide the next stage of care, home hospice palliative care and we learned we were not alone in our journey. Instead was part of a larger HPE family. We were welcomed into Families For HoPE. We were part of the -O” team working to change HPE into HoPE!

The next several months were rather tumultuous and exhausting. She spent her one-month birthday in the Children's Hospital of the King’s Daughters (CHKD) where she received her first EEG. What girl does not want a medical procedure for her birthday? Over the next several months, she spent nearly every other week checking into the emergency room and transferring to in-patient care while we worked to gain control of seizures, sodium levels, body temperature, and other symptoms of HPE.

Finally in May 2015, Charity had a breakthrough in treatment. After getting her G-Tube (the tube that feeds directly into her stomach) installed and hemangioma removed, she met Danielle Goldblatt-Burch, her miraculous dietician, who started her on a ketogenic diet. The ketogenic diet is a centuries old therapeutic diet used primarily to treat epilepsy. It is a relatively simple principle of excluding high-carbohydrate foods such as starchy fruits and vegetables, bread, pasta, grains, and sugar, while increasing the consumption of foods high in fat such as nuts, cream, and butter. The most critical factor of the diet is ensuring all forms of carbs are eliminated, including absorption from creams and medications. Through the steadfast dedication of Danielle, we have all been trained in what is acceptable and not. Even Morgan knows that “Charity is allergic to sugars and carbs.” After all the variations in medications and multiple hospital stays, this single action seemed to have the greatest improvement on her life. While the seizures are still a daily occurrence, they are significantly reduced. Charity went from week long in-patient hospital stays every other week, to being hospital free for over a year!

And we have fully ‘seized’ this past year. Charity traveled cross country multiple times for various family events, including a family cruise to celebrate her great-grandparents’ 50th wedding anniversary. With the help of Chesapeake's Early Intervention program, the family started occupational therapy to improve mobility and maintain flexibility. Her occupational therapist, Dana Blair Carroll from Play To Grow, coached us on ways to incorporate therapy and exercise into everyday activities. With assistance, she even crawled a few times with reciprocating leg movements, something neurologically “impossible” for her to do.

And now we are finding ‘a new normal.” I’m not sure if someone mentioned those words to us or if we
made them up. Or perhaps we just heard them elsewhere, in another time and place. But that is what we are about today, finding a new normal. On August 21, Charity’s journey took another turn, and we are on to searching for a new normal. Looking back, we should have known something wasn’t just right. Or perhaps, we were all too used to things not being quite right. She had been mostly calm and quiet for the week. She was sleeping quite a bit, with a few breakthrough seizures. She was not holding her ketogenic feeds down, so she was on Pedialyte. And she had been several days without a bowel movement. Her breathing was a bit shallow, and she was on a little oxygen at home. Again, none of this being new for Charity or us, we all simply played our parts, as we had been doing since she was born. Except this time, Charity decided to take us in a new direction. That evening, as Charity lay sleeping, she took her last breath. While we rushed to her aid, turning up the oxygen, starting CPR, and dialing 911, she peacefully traveled to the next portion of her journey. And now we struggle on ours.

Some 2 months later, we are still searching for a new normal. After funeral plans, visiting friends and family, meals, cards, and all the things that go with a life-changing event, the world continues on. Milk still needs to be purchased. Cats still need to be fed, and the fish tank needs to be cleaned (those two thoughts probably shouldn’t be together). Vendors still call to replenish supplies. And just about the time you believe that you have notified everyone who needs to know, literally 9 weeks to the day, you receive another phone call. This time, after being on the waiting list for over a year, Charity has been approved for an iStat machine to help manage sodium levels. Ironic. And so you tell the story, one more time. Perhaps a little easier, but no less painful.

As we sit and write this, we reflect back on the nearly three years since we first learned of HPE. We are so thankful for the many wonderful people who have been brought into our lives, all of the doctors, nurses, therapists, friends, and complete strangers. We are grateful for all of the support we have received. We have grown in our faith and confidence in God, realizing that we were given the opportunity to say YES to life when others may have said no. And, perhaps the biggest thing we have learned is that in so many ways, Charity was a very typical child. She refused to listen to adults and do what they expected her to do.

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FINDING A WAY WHEN THERE SEEMED TO BE NO WAY:  
THE JOURNEY TO PALLIATIVE CARE FOR OUR SON, SILAS

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Silas’ Mother  
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We were beyond thrilled to be expecting a second son, due May 2014. Our older son, Elliot, was five years old, and we had been trying to grow our family for a couple of years. During our routine 20 week anatomy scan the ultrasound tech commented that she couldn’t get all of the needed images and referred me to a maternal fetal medicine specialist for the following week. We went into that appointment with no fear or concerns just assuming that more images were needed. During that long ultrasound the maternal-fetal medicine doctor told us -there is something very wrong with your baby’s heart.” He explained that he believed our baby had Hypoplastic Left Heart Syndrome (HLHS) and described a bit about the details of the diagnosis. We left that appointment shocked, but ready to research the diagnosis that our son had been given. The maternal-fetal medicine doctor referred us to a pediatric cardiologist the next week for an echo cardiogram and definitive diagnosis. Our heads were spinning. How quickly we had gone from elation to panic. I remember looking blankly at the piece of paper with Hypoplastic Left Heart Syndrome scribbled on it and just staring at those unfamiliar words.

Over the weekend we spent many hours researching and learning about HLHS in preparation for our appointment with the pediatric cardiologist. My husband and I are both high school teachers with graduate degrees, so the research aspect came naturally to us, and we desperately wanted to know everything we could about this diagnosis that our son had been given. We wanted to know what questions to ask as we had a lot to learn about the workings of the heart.

After a fetal echo cardiogram that took well over an hour, the pediatric cardiologist confirmed the complete/severe HLHS diagnosis. After the HLHS confirmation, we struggled in making a decision from the impossible choices in front of us. We asked many questions about surgical options, our baby’s quality of life, and every other inquiry we could think of as it pertained to what the reality of the diagnosis meant for our son and our family. The pediatric cardiologist patiently answered all of our questions and said to us at one point, -you two are asking questions that I rarely hear parents ask.” The pediatric cardiologist began discussing the three-surgery process in the treatment of HLHS, as if that was our only option for our son. Having spent hours researching the weekend before, we had learned so much about the realities of HLHS and felt deep in our hearts that beginning the surgeries was not the path we wanted for our son. We asked the pediatric cardiologist about the option of -comfort care‖ or perinatal palliative care. He looked at us and quickly told us that there wasn’t a program in our state of Oklahoma to —do that.” We were devastated in where to turn for support and answers.

After a long time in discussion with the pediatric cardiologist about every aspect of our son’s specific defects we left that appointment in utter shock, trying to process what this diagnosis meant for our precious son and knowing deep in our hearts that just because something can be done medically that it doesn’t always mean it should be done. The more we read about the surgeries that attempted to temporarily keep his heart going the more we realized that we could not ask our son Silas to -fight‖ a battle in which he would never win, a battle that would never result in him getting better, a battle that would never lead to a cure. We couldn’t do that to him. We couldn’t ask him to do that. It was too much, way too much. We spent a few weeks making phone calls and trying to decide where to deliver our son out of state, since we knew that comfort care was our choice and the state of Oklahoma did not have a perinatal program in place in 2014. Thankfully, we connected with a neonatologist in a local hospital who recently came from another state and had years of experience in perinatal palliative care. We met with him, explained our wishes and he assured us that the choice of comfort care for Silas’ diagnosis was something he felt very comfortable with and ready to lead Silas’ care once he was born. Once we made the decision for perinatal palliative care, although our hearts ached deeply, we knew that it was the right and best parenting decision for our son.
We then put all of our focus on giving Silas the best life we could with his diagnosis. For us, that meant no medical intervention. Based upon our research, our faith, and our ethical concerns, we said just because it can be done medically doesn’t mean it should be done medically. We wanted Silas to live a life full of only love and entirely in the arms of those who loved him dearly. Silas lived an amazingly beautiful yet tragically short 56 hours in the arms of those who loved him deeply. All he knew was love. He had no medical interventions and knew no pain. We took hundreds of pictures and read books to him; his big brother, Elliot, blew bubbles for him to see, and Silas was snuggled with kisses his entire life.

Our lives have forever been changed by HLHS. My husband and I knew we had to make the best decision for Silas, our older son, and our family. It will never be an ‘okay’ decision that we had to make. There is nothing okay about the choices we had to make. Deep in my soul, I am certain we gave Silas the best life we could with his terrible diagnosis. Silas died peacefully skin-to-skin on my chest as I sang over him. The tragedy and beauty of those moments are with me forever. We will cry a thousand tears and carry years of pain missing Silas, so that he never cried and knew no physical pain, and for this I am beyond grateful.

Silas inspired great change in our state. His story was the catalyst for the creation of The SILAS Program at Hillcrest Medical Center in Tulsa, Oklahoma. The team of medical professionals (led by the neonatologist that helped our family and many other wonderful medical professionals) walked through our journey and took care of Silas, moved by the beauty and hope found within perinatal palliative care. Thus, the only hospital-based perinatal palliative care program in the state of Oklahoma was created shortly after Silas’ birth and death. The acronym of the SILAS program stands for: Strongly Impacting Lives Against Suffering. This ideal is the epitome of perinatal palliative care. It is a great comfort to know that other families in our state now have the medical and emotional support to give their babies a life full of love. All Silas knew was love, and because of his legacy, so will all the other babies in the SILAS program.

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CARING FOR FAMILIES EXPERIENCING PERINATAL LOSS

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4 years ago, I gave birth to my second son. He was stillborn at full term, a mere few hours after hearing his heartbeat loud and clear at my last prenatal visit—an experience that took me to the edge of losing my sanity and hope. I did not know the journey that his birth and death would take me on, nor that grief would awaken a whole new part of me. *You can read the full story of his birth here.*

Now, my work is in telling the stories of motherhood in all their forms and variations. As the years have gone by and my own journey of processing loss has become cradled gently among the journeys of countless women who I’ve been able to walk alongside of, I have found that grief can become more a friend than an enemy, more a guide than a stranger.

Being in this space with women is a gift, mostly to receive. I’ve held the hand and heard the stories of many mothers who have faced loss and find that each has more to offer me than I could ever offer them. Loss can bring us to our most elemental selves, to a purity of understanding and consciousness that is difficult to access in our normal everyday lives.

This work and my own experience have given me the opportunity to observe how critical medical care provider support and response to families facing loss is. Many of these observations have been discussed with collaborative health care professionals, as well as with the women and families who have experienced loss.

Here are some strategies I believe can make all the difference in allowing providers to offer the most emotionally accessible and thoughtful care possible.

**Follow your intuition in gauging what level of communication and support the family is looking for from you personally**

Walking through perinatal loss with women doesn’t come with a handbook. It requires a deep connection to our intuition, something that isn’t always readily accessed. We live in a culture that isn’t accustomed to identifying and sitting with experiences of grief, and people around someone who has experienced loss are uncomfortable until signs of having ―moved on‖ are obvious.

One of the cornerstone impulses of our culture is to have something to say: ―Everything happens for a reason.‖ ―You’re young; you’ll be able to have another baby.‖ We mean well—we just want to help the pain go away. But the truth is, the pain isn’t going to go away. My husband, who lived through those dark days with me, says ―embrace the horror.‖

I remember the morning shift nurse after my son’s stillbirth, a mousy woman who showed up and while bustling about the room saw fit to immediately tell us about having lost a baby herself 20 years ago. She launched into a pithy 10 minute sermon about how this will all turn out for the best and how someday I’ll be able to help other people, ―like her.‖ Ironically, she could have been the most equipped to provide empathic, intuitive support to me, but instead her presence caused me additional pain and anxiety. After a while I interrupted her and asked if I could have my baby back.

In stark contrast to that experience, the nurse I remember positively is the one who gripped my hand during contractions in the night and never said one word to me; the one who knew the bright lights and cramped room of the closest emergency hospital would be in my nightmares for years to come. We would have never shared that room under different circumstances. She knew that her very existence next to me meant it was the worst day of my life.
Some women (and families) will want to talk about their experience of what is happening or has happened. Others will not. Some will feel like you are a central figure in the pain they are enduring, either as a conduit of it or as a comfort from it. In either case, your intuition can guide you in knowing what kind of emotional and physical support you can provide.

**Offer information and important decision-making requirements with sensitivity**

-Grieving parents want staff to demonstrate sensitivity and empathy, validate their emotions, provide clear information, and **be aware that the timing of information may be distressing**. Parents want support and guidance when making decisions about seeing and holding their baby. Sensitivity, respect, collaboration, and information are essential throughout the experience of stillbirth. “Study: Caring for families experiencing stillbirth: Evidence-based guidance for maternity care providers

Families facing perinatal loss face many difficult decisions in the context of overwhelming grief and frequently have a diminished capacity to absorb and retain information. Autonomy in decision making should be strongly encouraged, while acknowledging that the emotional engagement required is monumental, especially for mothers. Gentle, repetitive reminders and presenting information in different lights can be helpful for parents that feel like their world is crumbling around them.

In an emergency situation, the need to aid women and families in time-sensitive decision-making has to be balanced with a gentle, intuitive presence. This is an age-old dilemma—how do you hold that space and still get your job done?

**Allow an extended window for families to consider how they want to interact with their baby**

There was once a time where stillborn babies were whisked away, where women were given medication to prevent lactation, where families were instructed to “forget and move on.” While these days are long past and we are horrified that this was once the standard of care, it’s important to also remember that each individual mother (and partner/family) will have their own ease or discomfort with proximity to “unnatural” death. It is important not to assume that women will absolutely want to hold their deceased baby, for example, although evidence suggests that giving the opportunity has a great impact on maternal mental health outcomes.

In my own personal experience of walking through perinatal loss with women, most do choose some amount of contact with their baby, and many wish that they had opted or allowed for more time. This is why I highly recommend offering an extended or repeated window of opportunity for mothers, partners, and family to interact with their baby. Funeral arrangements are so quickly begun in a hospital setting and delaying these conversations allows families time to orient themselves to what feels natural to them in creating memories with their child. I have known many fathers, for example, to feel uncomfortable with holding their baby initially, only to change their mind a couple of hours later (or to later wish they had).

It is also so important that families do not feel pressured to interact with their child or to express their grief in a certain acceptable way, and equally important for care providers not to allow their personal values to influence their care of and communication with the family. Cultural practices, belief systems, personality, family dynamics, and mental health issues all play a role in how a mother and her family may express their grief and their wishes for attending to arrangements for their deceased baby. Providing appropriate options for creating memories and ample/repeated opportunity for these to be digested and engaged is key.

Commit to cultivating a generous respect for the individuality and diversity of grief, despite your own values, experiences, or training.

**Develop a communication plan within your staff to ensure all members are aware of when a loss has occurred**
I don’t claim to know the inner workings of a labor and delivery ward. But I know there has to be a way for the social worker not to burst through the door with “congratulations!” on their lips. This happened to me and I’ll never forget the look on her face when she figured it out. There was no taking back the damage done—various hospital staff apologized to us over the course of the following hours, and each new piece of paperwork was brought more timidly than the last. They knew it was a fatal error but they seemed helpless to have prevented it.

Whatever it takes to prevent this, make it happen. No mother should have to show up to a postpartum appointment with their provider only to be asked “how the baby is doing” or “how breastfeeding is going.” These can be pivotal moments for perinatal loss survivors in confirming that they can get the support they need from their care providers or that they cannot.

…I remember the initial weeks after my stillbirth as an undoubtedly dark time, yet the care I received from my midwife during those weeks sticks with me as the most compassionate, present and intuitive care I have encountered. She came to my home; she touched my body with compassion. She made it a priority to check on my well-being for months to come. A year later, on the first birthday of my son (who she shared a birthday with); I received a letter from her describing how she remembered my son and that day. It was the difference between someone feeling sorry for you and someone sharing an experience with you.

While some aspects of this model of care may be outside the abilities of a standard health care professional or practice, any person can allow intuition and compassion to guide the care they provide to women and families experiencing loss.

Please check out the podcast I host at www.motherbirth.co - exploring the stories of the transformation of motherhood.
PEARLS FROM PARENTS

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After working with bereaved parents for many years I am constantly amazed at the depth of their wisdom and their words of encouragement for others who have lost a baby. It never seems to matter the baby’s gestation or diagnosis, or if the baby lived after birth. What matters is the unifying loss and grief that binds these parents together. I have asked bereaved parents to share the things that they would like others to know about their journey and also the pearls of wisdom they learned along the way. The following are some of these simple, yet profound thoughts.

I would like others to know that:

Grief is a journey: it is cyclical, not linear…. I can be grateful and grieving at the same time…. Loss is more common than you realize…. I want you to ask me about my baby, just like you would any other child…. Our baby is forever and always a part of our family…. Both mom and dad want you to ask them how they are doing…. One child never replaces another. Our daughter still has a strong and permanent place in our family…. We move forward but we don't move past…. Just as I am mom or dad, don't forget that you are grandma and grandpa and aunt and uncle…. Talking about her and opening up has been so helpful to us…. Setting up a donation fund has been a gift that allows us to give forward…. Grief is a long journey, one that never ends, but one that does get easier with time…. The pain does dull after time, but it never fully goes away. You adjust your life to live with it instead of running from it…. Sometimes time seems to speed by and other times it seems to stand still. No matter which end of the spectrum I am on, my baby is always right in the center, never forgotten. …Life will never be the same…. When there are no answers or anything you can fix, just listen to me…. I want you to call me baby's mother or father, I don't hear it often enough…. I hate being told that everything happens for a reason or that time heals everything…. At the holidays save a place at the table for my baby…. When my baby passed, I like to think that God's heart broke first…. Do not fear the tears, be they your tears or mine….

Pearls of wisdom for parents who have lost a baby:

You are the keeper of your baby's memory…. It's OK to cry even if it's in public, like Target…. You are a wonderful mom and dad… Give yourself plenty of grace…. Let people love you. Don't push them away in your hurt…. Many may not know how to react. Try to be kind and forgiving, as hard as that may be. They care, but don't know how to show it…. It's OK to remember/talk/honor your baby however you wish or feel. Our society does not do a good job of talking about or recognizing death and the corresponding grief…. Find a family grief group for your kids, it's so helpful…. Stick together, mom and dad. People grieve differently…. People will say things that anger and frustrate you…. Go to group or connect with other families going through a similar loss…. Find a way to remember and honor baby and do that when you need to…. Breathe, meditate, pray…. There are hidden gifts here as hard as they may be to imagine…. Do something monthly on your baby's birthday…. Have a room or area of your house, dedicated to the memory of your baby and visit it often…. Journal, write about your feelings especially if you can't talk about them…. Go on a road trip in memory of your child…. Take one day at a time. Walk your journey slowly. Take time to remember, be angry, grieve, and love…. Never worry about what the world thinks grief should look like. Take your time…. My baby and yours both dance with the angels…. You are not alone. There is support and help available for you on the journey…. Remember the good times…. Emotions come in like weather, don't fight the storm, embrace it …. Don't let other people get you down…. Some days you won't feel like doing anything and that's OK…. Everything will remind you of your baby…. Others have gone through this before you…. Use your child's name as much as possible…. Take time off of work and be with your family…. It's OK to feel joy and be happy again…. The loss of your
baby is not your fault. Let go of the guilt. Have a bonfire and write the word “guilt” on a piece of paper and throw it in the fire…. Cherish everyday as a gift from God…. Cherish your baby forever and celebrate her life…. It is amazing what matters now….

Bereaved parents have remarkable insights and we can learn from them. We are blessed to be able to take this journey with them. May we continue to learn from them in hopes of being better prepared to help.
Twenty years ago, in 1997, the idea of perinatal hospice made its appearance in the medical literature for the first time. Inspired by a patient who chose to continue her pregnancy with a baby diagnosed prenatally with Trisomy 18, her medical team reflected on the care they had provided and proposed a model of support to improve the care for other patients to come.

"Because of early diagnosis of lethal fetal anomalies, the process of providing care for a grieving family no longer begins at birth, but at the time of diagnosis," they wrote. "The concept of perinatal hospice allows for continued support for the family from the time of diagnosis until the death of the infant."¹

Ten years ago, in 2007, the concept had begun to spread enough that this ChiPPS e-Journal devoted three full issues to perinatal loss, including articles about prenatal diagnosis, prenatal advance care planning, birth planning, and discussion of perinatal hospice and palliative care.² An entire issue was devoted to perinatal palliative care in 2013.³

Now, in 2017, the growth of this practical and compassionate model of care has been exponential. Nearly 300 perinatal hospice and palliative care programs are on the international list at perinatalhospice.org; training and protocols are available; and word has spread through numerous journal articles for medical professionals as well as many stories in mainstream media such as The New York Times, MSNBC, and The Washington Post.⁶

Some background and definitions: Perinatal hospice and palliative care is a model of support for parents who choose to continue their pregnancies despite a prenatal diagnosis that indicates that their baby has a life-limiting condition. It integrates the philosophy and expertise of hospice and palliative care with best practices in perinatal bereavement care for miscarriage, stillbirth, and infant death.⁷ This comprehensive support is provided from the time of diagnosis through the baby's birth, life, and death.

This support can be thought of as "hospice in the womb" (including birth planning, emotional support for the family, and preliminary medical decision-making before the baby is born), as well as more traditional hospice and palliative care at home after birth (if the baby lives longer than a few minutes or hours). It includes essential newborn care such as warmth, comfort, and nutrition. It can also include medical treatments intended to improve the baby’s life. If and when the baby dies, many parents choose to take photographs and collect footprints and other keepsakes, with the assistance of hospital staff. (In hospitals across the U.S. and elsewhere, helping families create memories during this fleeting time is considered best-practices standard of care.) This extra layer of multidisciplinary support can easily be incorporated into standard pregnancy and birth care. Rather than "doing nothing," perinatal hospice is an extraordinary form of physical and emotional care that honors the baby throughout his or her entire natural life as well as honoring the family.

When this model of care was first proposed, it was named perinatal hospice. For many of these babies, their lives after birth will be quite brief, so hospice is an apt description of the care they will need. As the idea spread, and as palliative care became a medical subspecialty in its own right, this concept has also come to be called perinatal palliative care. Of course, "palliative care" is a broader term that includes end-of-life hospice care—all hospice is palliative care, but not all palliative care is hospice. Like palliative care for adults, perinatal palliative care is not limited to end-of-life care and can include medical treatments intended to improve the baby's life. This is especially important for life-limiting conditions such as Trisomy 13 or Trisomy 18 that are often dismissed as "incompatible with life," a "lethal diagnosis," or a "fatal fetal abnormality," but for which extended survival is sometimes possible. Because palliative care is a broader term, and also because the word "hospice" unfortunately carries negative connotations for some people, some feel that calling it perinatal palliative care (or something else entirely) can be more comforting. One
could argue that either term can be appropriate.

Among the indications that this model of care is reaching a critical mass:

- Professional training is available from multiple sources, including the Certification in Perinatal Loss Care from the Hospice and Palliative Nurses Association as well as online training from the International Children's Palliative Care Network and the National Hospice and Palliative Care Organization.
- Detailed examples of program development and care pathways have been published by organizations including Resolve Through Sharing Bereavement Services, Together for Short Lives (U.K), and others.
- The American Academy of Nursing published a policy brief in 2016 endorsing the concept and calling for program development, allocation of resources for professional training, a credentialing process, and increased public awareness.
- Updated prenatal testing practice guidelines from the American College of Obstetricians and Gynecologists and the Society for Maternal-Fetal Medicine recommend that post-diagnosis counseling for parents should include the option of perinatal palliative care.
- The international list of programs at perinatalhospice.org, which began with 27 programs in 2006, has now grown to nearly 300 programs in 47 U.S. states and 22 other countries. Program structures vary. Some freestanding hospices provide this support, while in many hospitals it is a natural extension of existing high-risk pregnancy care, existing perinatal bereavement protocols, or existing palliative care programs for pediatric patients.

When offered the option of perinatal palliative care, growing numbers of parents—in one study as many as 85 percent—choose to continue their pregnancies and receive this care. A recent study in France found that the number of parents who continued pregnancies despite a severe prenatal diagnosis has risen 135 percent. As one researcher concluded in a state of the science overview published in the *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, "The science suggests that perinatal palliative care is welcomed by parents and is a medically safe and viable option."

Even so, much work remains. Barriers include lack of awareness among caregivers and parents; lack of referrals from obstetricians; lack of integration into maternity care in general; precarious funding; lack of professional training; assumptions that continuing a pregnancy with a life-limiting fetal anomaly could harm a mother's physical or emotional health; and assumptions that this approach would cause a baby to suffer. All of these barriers and concerns can and should be addressed as this model of care continues to develop in the future.

In closing, on a personal note: Back in 1999 I needed this kind of comprehensive support for myself, and nothing like it was available for us. My husband and I had learned through prenatal testing that our son, Gabriel, had an incurable heart defect. I searched for websites, books—anything—for reassurance from someone else who had gone through this experience of continuing a pregnancy and simultaneously preparing for birth and death. There was virtually nothing. Although the idea of perinatal hospice had been proposed in the medical literature two years before our baby's diagnosis, the concept had not yet spread. Fortunately, we had an empathetic nurse who affirmed for us that we still had a profound opportunity to parent our baby. She helped us with our birth plan and helped coordinate communication with the rest of our care team. We created a sort of perinatal hospice experience for ourselves, even though we didn't have those words for it at the time. I always say that Gabriel lived for nine months before he was born and for two-and-a-half peaceful hours afterward. He knew only love.

I eventually wrote a memoir, *Waiting with Gabriel* which was the kind of story I had been searching for while I was pregnant. A few years later, I put my journalistic hat back on and collected stories from more than 100 parents for *A Gift of Time: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief*. It's like the book *What to Expect When You're Expecting* when this isn't what you were expecting at all. I invited developmental psychologist Deborah L. Davis, Ph.D., to co-author the second book with me because I had been helped greatly by her book *Empty*...
Cradle, Broken Heart: Surviving the Death of Your Baby and Loving and Letting Go. In 2006 I also founded the website perinatalhospice.org http://perinatalhospice.org, hoping that it would become a place for parents and caregivers to find resources as well as a list of programs to help parents find the support they need as close to home as possible.

My goal is that my website will soon become unnecessary because every hospital and clinic that cares for pregnant women will skillfully and compassionately provide perinatal palliative care when needed. Until then, my hope is that these books and my website will help at least one other parent feel more empowered and less alone.

Amy Kuebelbeck is editor and founder of the website perinatalhospice.org, a clearinghouse of information for parents and caregivers. She is lead author of A Gift of Time: Continuing Your Pregnancy When Your Baby’s Life Is Expected to Be Brief (Johns Hopkins University Press, 2011) and author of the memoir Waiting with Gabriel: A Story of Cherishing a Baby’s Brief Life (Loyola Press, 2003). She has been invited to speak at numerous medical conferences across the U.S. and elsewhere. She also moderates a perinatal hospice email group for caregivers, which currently has more than 400 members. She lives in St. Paul, Minnesota, and can be reached at info@perinatalhospice.org.

References:


13. A Perinatal Pathway for Babies with Palliative Care Needs from Together for Short Lives (U.K.), developed in conjunction with ethicists and clinicians working across obstetrics, antenatal and neonatal care, and children’s palliative care. http://www.togetherforshortlives.org.uk/professionals/resources/11598_perinatal_pathway_for_babies_with_palliative_car e-

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A BRIEF OVERVIEW OF PERINATAL PALLIATIVE CARE RESEARCH AND PRACTICE

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Perinatal palliative care (PPC) is a compassionate and supportive model of care delivery that typically spans the time from prenatal diagnosis of a life-limiting condition through the infant’s death (Denney-Koelsch et al., 2016). The principles of PPC support parental control of their pregnancy and the goals they desire for the baby (Wool, Repke, & Woods, 2017). PPC incorporates all aspects of a parent’s world of meaning, including physical, emotional, spiritual, moral, and cultural. The purpose of this article is to provide the reader with examples of current evidence-based research, suggestions for a clinical practice framework, a case study, and rationales to support the need for competencies.

Perinatal Palliative Care Research

PPC developed at the urging of parents and care professionals who saw a need for better support options when babies had short life expectancies (Denney-Koelsch et al., 2016). Over the years, research has focused on many aspects of PPC—among them, diagnoses, PPC models, program outcomes, and patient needs and satisfaction. Findings from current evidence-based research addressing programs, parent satisfaction, policy, treatment choice, and birth and advance care planning are provided here.

Programs

The National Consensus Project for Quality Palliative Care lists eight domains as essential to quality care (2013). Relying on these domains, Wool and colleagues (2016) conducted a survey of PPC programs to determine the degree to which they were in alignment with the domains, the disciplines involved, and the services provided. They found that programs relied on an interdisciplinary team, helped parents develop care goals, offered bereavement services, addressed spiritual needs, considered cultural needs, and advised parents about the dying process.

In another study using this survey data, researchers focused on Domain 1, Structure and Processes of Care. When asked what care components they believed parents found most important, survey respondents reported: respect for parent preferences and choices, support, respect for the infant, and opportunity to parent (Denney-Koelsch et al., 2016). Researchers also identified expected outcomes for families, the most frequently reported of which were physical and psychosocial support, and satisfaction with the decision-making process (Denney-Koelsch et al., 2016).
Parent Satisfaction

Patient-centeredness is a tenet of PPC (Wool et al., 2016). Evaluating care is heightened when a family's own care experience is primary. Wool and colleagues (2017) surveyed parents who continued their pregnancy after diagnosis of a life-limiting condition and found three predictors of parent satisfaction: consistent care, compassionate care, and emotional assistance (Wool et al., 2017).

Predictors of care satisfaction identified by Wool et al. (2017) are linked to the work of Marokai, Kaparian, and Kennedy (2016), who studied prenatal counseling as a mechanism for reducing psychological distress. Because their literature review showed that counseling reduced anxiety, they made these recommendations: (1) offer counseling when parents learn diagnosis, (2) use knowledgeable, empathetic professionals, (3) provide comprehensive information about the diagnosis, and (4) give consistent information at family meetings using common language. These ideas are consistent with PPC research.

Of particular interest to researchers, practitioners, and health care institutions is an accurate accounting of PPC use by women and families. Little data exist, but two recent studies provide helpful insights. Marc-Aurele, Hull, Jones, and Pretorius (2017) reported that 11% (N=332) of eligible women in the tertiary center studied were offered PPC. A slightly higher percentage (19%; N=140) was documented by Bourden and colleagues (2017).

Policy

Health policy development leads to standards of care—the building block of exemplary medical care. An American Academy of Nursing policy brief advocated for PPC's recognition as the standard of care for families continuing pregnancies (Limbo et al., 2017). Accordingly, the policy provided six recommendations to further PPC's growth: development of effective models, care team education, provider reimbursement for PPC, nurse designation as a key team member, promotion of public awareness, and credentialing.

Treatment Choice

Decision making is central to PPC. Ideally, parents will have all available options presented when they learn their baby's diagnosis. Provided unbiased and detailed information, some parents will choose to continue with PPC, while others will terminate the pregnancy. PPC may include creating a birth plan and/or advance care plan, interactions with the baby, involving siblings, and creating keepsakes, among other possibilities. Whatever choices are made, parents maintain control and are supported in knowing they were able to legitimize the pregnancy and fulfilled their role in lovingly caring for their child (Hasegawa & Fry, 2017).

Côté-Arsenault and Denney-Koelsch (2016) discovered that a decision-making goal for parents was having no regrets. They wrote, “. . . all wanted to avoid having regrets and hoped to feel they did the best they could for their baby” (p. 6). Parents worked to understand the diagnosis, considered the prognosis, questioned whether their baby's condition would be as predicted, and ultimately chose a plan that reflected love for their baby and respect for their birthing experience.

Birth and Advance Care Plans

PPC involves the dual process of tending to the pregnancy while preparing for death. Shifting between these two states can cause significant emotional turmoil. Care providers must be prepared for such reactions and normalize the couple’s experiences and help them see their baby as beautiful and special.

Writing a birth and advance care plan is a proactive process. The plan describes the parents’ choices for laboring, delivery, postpartum, and neonatal care (Côté-Arsenault & Denney-Koelsch, 2017). It is a guide, not a prescription, and details acceptable medical and nursing treatment, preferences for pain assessment and relief, and parents’ wishes for interacting with their child. It also can spell out goals for end-of-life care, such as organ and/or tissue donation, testing, naming the baby, memory-making, and
remembrance rituals.

Preparing to welcome their newborn while facing the possibility of saying goodbye places families in a dual reality. Every moment with their baby—whether born alive or dead—counts. Families need support and encouragement to make plans that leave them with precious lifetime memories and no regrets (Côté-Arsenault & Denney-Koelsch, 2017).

Implications

Interdisciplinary Competencies

Building knowledge in health care occurs when clinical practice and research merge. The work highlighted in this article demonstrates that the PPC field continues to create and refine paradigms that support caregiving competencies. PPC teams unite the disciplines of medicine, nursing, chaplaincy, social work, and other specialties. This collaboration requires that staff be competent in their area of expertise and functionally present for the family. A proposed model for designing PPC competencies is guided participation (Pridham et al., 1998), a teaching-learning clinical practice or method in which an experienced person guides the learner in developing or enhancing competencies. Guided participation has been the subject of much research, resulting in the identification of the following competencies, which can be developed in both teacher and learner: (a) being with, (b) knowing and relating to the other, (c) communicating, (d) doing the task, (e) problem solving, and (f) regulating emotions (Pridham et al., 1998). These competencies may affect the way care is delivered, one’s response to care, how the future is viewed, and how the competencies may enhance the goal of living without regret.

Conclusion

PPC involves multiple relationships, each of which provides the opportunity to engage meaningfully with another at one of life’s most trying times. With increasing interest in policy, research, planning, parent satisfaction, decision making, program development, and caregiver and parental competencies, PPC is seen as the opportunity to be present as families care valiantly for their most vulnerable family member with love, grace, and generosity of spirit.

CASE EXAMPLE

I met Jane at the school where she worked, and later I saw both Steve and Jane (not their real names) at a coffee shop. Their son was diagnosed during pregnancy with a chromosomal condition called trisomy 18. After having built rapport and trust, I asked Steve, “What do you really want to do that your spouse, out of sacrificial love, can agree to?” I then posed the same question to Jane. Jane, a serious woman, deeply hoped to have her son baptized and confirmed by the priest who married them. Steve wanted to watch videos—a well-known classic movie comedy and an episode of a favorite all-star wrestler engaged in battle. Although a wide chasm existed between the sacred and worldly, both Steve’s and Jane’s wishes deserved respect. Together, we created a logistical plan to maximize chances for fulfillment of each parents’ hopes and goals.

I was called when Jane’s membranes ruptured at near term. I instructed them to bring the videos and alert the priest. The movie played during labor and delivery. Jane had asked me to assure her modesty, so I held a drape as Jay was baptized lying on his mother’s abdomen and the physician completed his repairs. Steve’s wish to watch wrestling with his son was achieved as we awaited delivery of the confirmation oil. The sweet baby died shortly after his confirmation.

Jane and Steve’s wishes were honored by staff throughout their PPC experience, so they were able to “have no regrets.” I believe the skill, compassion, and respectful commitment of our team allowed them to leave the hospital on a healthy trajectory of healing.

Contributed by Tammara Ruiz Ziegler, RN, CPLC, September 2017.
We acknowledge Cathy Mikkelson Fischer, MA, ELS, for editing the manuscript, and we thank those parents who graciously shared their stories.

References


Additional Resources

American Nurses Association (AMA) and Hospice & Palliative Nurses Association (HPNA) Call for Palliative Care in Every Setting. See: http://nursingworld.org/MainMenuCategories/ThePracticeofProfessionalNursing/Palliative-Care-Call-for-Action

Perinatal Hospice and Palliative Care website: http://www.perinatalhospice.org/home.html. See also: Resources for Caregivers Resolve Through Sharing (RTS) website: http://www.gundersenhealth.org/resolve-through-sharing/
THE DEVIL IS IN THE DETAILS:
IMPLEMENTING AN INTEGRATED PERINATAL PALLIATIVE CARE PROCESS

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Consider these two potential scenarios with suboptimal outcomes:

Madeline was pregnant with a fetus at high risk of fetal demise. She, her partner, and her health care providers collaboratively developed a perinatal palliative care plan. Madeline and her partner decided that they wished to be hopeful for a live birth. Included in their plan was the request that no fetal heart rate monitoring be done prior to delivery. Unfortunately, the palliative birth plan was not discoverable or accessed by the nursing staff admitting Madeline to the labor and delivery suite. Madeline and her partner were informed of the absence of fetal heart tones. They were devastated. (Their OB wasn't very happy either…)

Maria was pregnant with a son with Trisomy 18. To minimize their son’s suffering, she and her husband wished no life-prolonging measures after delivery. She wished to offer breastfeeding but did not wish any artificial tube feedings. Her birth plan included this information and was shared with the pediatrician. Their son was born alive and roomed as planned with his mother in her room. One of the nurses was distressed when the baby would not suckle and started to insert an NG tube. You can imagine the rest…

Developing a perinatal palliative care process that is continuous and coordinated across sites and providers is challenging, especially if there are multiple organizations involved. Successful implementation will ensure that all the effort is not in vain. Here are some aspects to consider in developing and implementing a successful program:

- Think carefully about who should be on your initial task force. Not only should you include providers and ancillary staff such as social workers and spiritual care providers, but also consider including parents, bereavement services, ethics, palliative care, home care, information services, registration, ultrasound, quality improvement, administration, and others appropriate to all organizations who might be involved in the care of the mother, baby, and family at all sites of care.
- Clearly describe those fetuses and newborns for whom you might care.
- Gather data for several years about affected pregnancies and outcomes.
- Identify barriers to optimal perinatal palliative care. While some of these may be unique to your organizations, some will be common. (Please see the Readers’ Corner article in this issue of the ChiPPS E-Journal.) The following were some of our identified barriers:
  - Lack of standard process especially around confirming diagnosis and informing family
  - Poor communication and coordination between providers and across sites of care
  - Inadequate decisional support
  - Lack of coordination and advance care planning after birth
  - Varying levels of staff education and skills in perinatal palliative care
  - Lack of appropriate tools to facilitate communication, and assess quality and satisfaction with care
- Describe the current and the ideal patient flow through the organization
- Develop plans for:
  - Decisional support and advance care planning: Skilled obstetric and newborn care providers should identify key decisions that many families will likely need to make once
the family decides to continue the pregnancy. These should be addressed in the advance
care plan. Some of these decisions include

- Management of the mother during the pregnancy, labor, and delivery
- Intervention in event of fetal distress
- Site of delivery
- Attendants at delivery
- Specific resuscitation at birth
- Site of newborn care
- Life-prolonging measures desired including artificial nutrition and hydration
- Postnatal care including feeding plan and home care services
- Mementoes, memories, rituals, and ceremonies
- Expect challenges: Anticipate who might be involved in implementing key
  aspects of the plan, and involve them as decisions are made. For instance, if the
  family has specific preferences about doing (or not doing) a Cesarean section in
  event of fetal distress or about newborn resuscitation, include the neonatal care
  providers in the decisional process. They shouldn't be surprised when they walk
  into the delivery room. Anticipate plans that some staff may feel are morally
  objectionable (as the second case above). Most organizations have policies
  addressing responsibilities and options of staff members who have religious or
  moral objections to the plan of care.

- Communication: With the electronic medical record, it is easier to disseminate notes and
  plans to all current and future providers. There are no HIPAA barriers to communication
  between providers. Ensure that the information is impossible to ignore, in the same way
  as allergies are "in your face" in the electronic medical record. Being able to find
  information if you seek it is not enough! We embedded the palliative care birth plan into
  the routine birth plan that all caregivers routinely access. If the plan is to be implemented
  at another organization, seek their input into how to communicate the plans to all who
  need access to the information.

- Coordination of care: a "key coordinator" for newborn care is very helpful after birth. This
  person provides continuity, logistical support so that the plan is followed, family support,
  and also informs and coordinates providers who may be from multiple organizations.

- Documentation: Develop perinatal palliative care note templates for antenatal
  consultation and care, birth plan, and newborn advance care plan. If possible, link the
  mother and baby medical record for the first several months of life. This was possible
  using the EPIC electronic medical record system. It is generally only feasible if mother
  and baby are cared for in the same organization.

- Quality improvement: Incorporate quality measure fields into the note templates.
  - Develop and distribute parent education materials about the program
  - Disseminate information about the new process to health care providers and provide needed
    education. The need for enhanced perinatal palliative care education, training, and skills,
    especially in communication, should be anticipated.

Now consider these alternative scenarios in an ideal world with a thoughtfully implemented perinatal
palliative care process:

Madeline's perinatal palliative care birth plan was integrated into her birth plan that was
automatically accessed when she was admitted. The nurses who had been in-serviced about this
possibility noted the lack of fetal heartbeat and notified the OB provider but not Madeline and her
husband. The provider notified the chaplain so that she could attend the family after the delivery
as had been planned. While Madeline and her partner were sad that their daughter was born
"still", they were pleased that their preferences had been honored, and that they received the
support that they needed.

Maria's feeding preferences for her son were noted in the palliative birth plan. As withholding
artificial nutrition was anticipated to be a potential challenge to some of the newborn nursing staff, the neonatologist who provided the antenatal counseling met with nursing leadership and planned several in-services for the nursing staff. She reviewed the medically and ethically appropriate feeding options with the nursing staff and emphasized that the family’s choice was ethically acceptable. She addressed concerns of staff, and reviewed organizational guidelines for opting out of care for moral or religious reasons. Informed and supportive nursing staff cared for Maria and her son. After 3 days in the hospital, they were discharged home as planned with follow-up by their pediatrician and home pediatric hospice staff.

Wikipedia (https://en.wikipedia.org/wiki/The_devil_is_in_the_detail) notes:
- The idiom, "The devil is in the detail" refers to a catch or mysterious element hidden in the details, meaning that something might seem simple at a first look but will take more time and effort to complete than expected and derives from the earlier phrase, "God is in the detail," expressing the idea that whatever one does should be done thoroughly; i.e. details are important.

Successful implementation certainly takes more time and effort than is expected! However, the effort results in an improved outcome for the newborn, the family, and the health care providers.
Empath Health | Suncoast Hospice began providing perinatal loss support in 2004. We're proud to have been one of the early perinatal loss pioneers. Our program has certainly expanded services over the years, particularly as the needs of our community have changed. As we look back on our history, we'll highlight some of the important lessons we've learned and what our future strategic plans are.

In 2004 Jane Parker contacted Stacy Orloff at what was then known as Suncoast Hospice (now known as Empath Health) to talk about beginning a perinatal loss program at Suncoast Hospice. Jane was a retired RN who had worked for many years as a high-risk labor and delivery nurse in the greater Chicago area. Jane's passion was supporting women and their families who had experienced a fetal demise. Jane was also a certified doula, in addition to being a high risk labor and delivery nurse. Through her work as a doula, Jane created a perinatal loss program that included doula presence at delivery and support groups for the grieving woman and her family. Jane was hoping to replicate that program in our area.

It did not take much to convince Stacy that this program fit perfectly with the mission of Suncoast Hospice and the pediatric services division of the hospice. Jane and Stacy began meeting regularly to strategize what Suncoast Hospice's program would look like. We felt it was important to include the community in the strategic planning process to ensure we could extend our reach to all significant stakeholders.

We began by inviting key community leaders and stakeholders (professionals and consumers) to a series of meetings. The meetings led to the formation of a community consortium. The consortium helped to sponsor a grand rounds presentation by a leading national NICU physician at our local children's hospital. Consortium members agreed to create three small work groups, believing that the small groups would help to inform the community about our new service and lead to innovative programming. The work groups assisted with developing our own perinatal loss curriculum, developing linkages for a speedy hospice admission if a child was born alive, and a focus on community engagement.

Consortium members became the strongest advocates for our perinatal loss program. With their support, our perinatal loss doulas became integrated into the labor and delivery units of our major hospitals. At the hospital where our primary high risk deliveries occur, the labor and delivery leadership added “contact the perinatal loss doula” on their “to do” list when a laboring woman presented at labor and delivery.

Referrals increased, including from genetics counselors, other healthcare providers, and consumers directly. We maintained our focus on labor and delivery. Our doulas were present throughout the labor. Our pediatric social worker was also often present, providing emotional support to family and staff. The doula, social worker, (and sometimes our pediatric nurse who attended as a volunteer photographer if desired by the parents) would gently bath the baby in lavender oil and dress the child for the family to hold.

The consortium continued to sponsor educational forums. We developed our own perinatal loss training program to bring in new doulas. We developed multiple series of support groups for bereaved parents,
grandparents, and siblings. We were successful in obtaining grant funding which allowed us to purchase clinical resources for the staff, volunteer doulas, and clients. Suncoast Hospice's sewing volunteers made clothing and blankets that was small enough to dress the birthed child. We purchased material that was especially soft for fragile skin. Frequently, children that were going to be buried were buried in the clothing or blankets we provided. Parents were also able to keep an extra item or clothing as a memory of their child.

There has been significant growth in the program over the last several years. Utilizing a Master's prepared social worker; we have expanded our perinatal loss counselling services and received a grant from the state-funded program for early intervention, Healthy Start. This allows women and their partners to receive individual counseling support in addition to our parent support groups and annual memorial services. The memorial services have expanded in conjunction with local hospitals and provide a forum for families who have experienced a loss to gather with others and mourn their loss. The number of doula volunteers has expanded to five fully trained with three more volunteers currently in training. A training curriculum has been developed utilizing multiple modalities to insure competency in caring for laboring mom and baby, supporting family during labor and birth, and coping with loss. The team is attending 8-15 births per month and many of those clients are then transferred into our Perinatal Loss Counselling Program.

As the program has grown, we have been asked to assist families in need of some additional support when there was an option of termination of the pregnancy due to severe fetal congenital anomalies. Local obstetricians were notified that if they had a family who required some assistance making a decision to terminate or continue the pregnancy Empath Health doulas, nurses, and counselors would be available. An example that shows the efficacy and value of this program involved a family we recently cared for. The family included a 24-year-old mother, father, and 4-year-old sibling. The mother had recently received a diagnosis of fetal anomalies including a large cystocele. The family was told by the obstetrician that there was very little chance that the child would survive the delivery and would certainly not survive for long after. Mom and dad requested time to think about it and their Healthy Start worker suggested they contact Empath Health. During the initial visit made by an RN, mom expressed the desire to give her baby every chance possible to live even if only for a few seconds. She and baby's dad wished to continue the pregnancy and also to have a cesarean section to insure the cystocele was not damaged during labor and delivery. After a great deal of discussion, the nurse and mom came up with a birthing plan that the mom then presented to her physician.

We remained in contact with the family during pregnancy, providing support as the due date came closer and mom became more concerned about the outcome. Staff was notified when mom went into labor and while we were unable to attend the birth due to the emergency C section, we arrived very shortly after. The baby survived the birth and mom and dad, with our support, were able to make decisions regarding the treatments and procedures the baby would undergo. After the baby was stabilized, she was transferred and cared for in our hospice care center while we trained the family to care for their little girl in their home. In spite of the severity of her defect, the baby survived this initial period and the family was sent home with the baby and support from the home pediatric hospice team.

The support provided prenatally as well as the immediate intervention after delivery allowed this family to enjoy their daughter for the months she was alive and ensure they had many good memories. We empowered the parents to make difficult decisions with adequate information and counselling, strengthening the bond between the baby and the family.

Our close relationship with the Healthy Start program has increased the number of referrals we are receiving prenatally as well as referrals for delivery support. We have continued to receive grant funding. The future holds some exciting new developments for our program. A recent grant received will allow us to expand our program to work with moms and families who are experiencing a miscarriage outside of a clinical setting. This program is specifically geared to parents who expect to experience a miscarriage at home. Kits will be provided for families to collect the fetal remains and honor the unborn child through burial or memorial service. Often the pregnancy is far enough along that the fetal remains have some limbs formed and visible. The trauma of this loss is different than other losses because there is no
recognition of the loss by parents, community or family. Counsellors will be provided to work with families during this very difficult experience.
NEONATAL PHARMACOKINETIC CONSIDERATIONS

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The neonatal period (first 4 weeks of life) represents a time of rapid change, development, and risk.
1 With advances in medical technology, infants are surviving that would not otherwise, increasing the need for palliative care in this population.
2 Premature or extremely low birth weight (Table 1) neonates typically require intensive follow up due to their complicated medical histories. Managing symptoms in the population can be especially challenging.

### Table 1. Classification of Neonatal Birth Weight

<table>
<thead>
<tr>
<th>Classification</th>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely low birth weight (ELBW)</td>
<td>&lt; 1,000 g (2 lb 3 oz)</td>
</tr>
<tr>
<td>Very low birth weight (VLBW)</td>
<td>&lt; 1,500 g (3 lb 5 oz)</td>
</tr>
<tr>
<td>Low birth weight</td>
<td>&lt; 2,500 g (5 lb 8 oz)</td>
</tr>
</tbody>
</table>

Some of the more common symptoms seen in the neonatal population include:
- Seizures
- Myoclonus
- Dyspnea
- Pain
- Secretions
- Thrush
- Reflux
- Gas
- Complications of congestive heart failure, including fluid overload

Since neonates are unable to express discomfort verbally, age-appropriate assessment strategies should be utilized. Often more objective measures can be utilized, such as heart rate (taking into account age specific normal values). For example, an increased heart rate may indicate pain in a neonate. Other indications of pain in a neonate include high pitched crying, brow furrowing, nasolabial bulge, and squeezing the eyes shut.

Non-pharmacological therapies should be first line in most situations, especially in infants and children. These strategies can include massage, music, and minimizing stimulation and painful procedures. Some therapies are more specific to the neonatal period, including swaddling, kangaroo care, nesting, and non-nutritive sucking (e.g., pacifier, sucrose). Neonates may also have difficulty maintaining their temperatures and may require warmth.

Neonatal pharmacotherapy is complicated by developmental limitations that affect the pharmacokinetics of most drugs. Infants should be monitored for clinical response throughout therapy and medications adjusted as needed. Medication doses will be determined based on gestational age, weight, and indication. Doses may need regular adjustment as patient weight increases. Neonates lose approximately 10% of their body weight during the first week of life. During this time, birth weight should be used for medication dosing.

Many pharmacokinetic parameters are altered in neonates (Table 2), affecting how the body handles drugs compared to older children and adults. For example, drugs are typically absorbed more slowly in neonates, therefore prolonging time to onset of action and peak levels. Hepatic metabolism (e.g. glucuronidation) is slower and matures around six months of age. Clearance is typically slower due to immature kidney function. At birth, serum creatinine levels are reflective of the mother’s renal function. Glomerular filtration rate increases rapidly in the first two weeks of life (maturation is slower in premature neonates). Once renal function begins to mature, serum creatinine levels are generally much lower than seen in adults since neonates have decreased muscle mass.
**Table 2. Neonatal Pharmacokinetic Alterations**

<table>
<thead>
<tr>
<th>Function</th>
<th>Alteration</th>
<th>Neonatal Function</th>
<th>Compared to Older Children</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Enteral Absorption</strong></td>
<td>Gastric Ph</td>
<td>High at birth (6-8) Decreases after 24 hours</td>
<td>Decreased bioavailability &amp; increased absorption of acid-labile drugs</td>
</tr>
<tr>
<td></td>
<td>Gastric emptying</td>
<td>Variable</td>
<td>Unpredictable rate of drug delivery to intestinal mucosa</td>
</tr>
<tr>
<td></td>
<td>Intestinal motility</td>
<td>Slower</td>
<td>Prolonged time to achieve maximum plasma concentration</td>
</tr>
<tr>
<td></td>
<td>Lipase levels &amp; bile salts</td>
<td>Decreased</td>
<td>Decreased bioavailability of lipid soluble drugs</td>
</tr>
<tr>
<td></td>
<td>Efflux transporters</td>
<td>Reduced</td>
<td>Altered bioavailability</td>
</tr>
<tr>
<td><strong>Rectal Absorption</strong></td>
<td>Permeability and first pass to portal circulation</td>
<td>Higher if administered into distal rectum; If deep administration, first-pass effect may alter bioavailability</td>
<td>Increased bioavailability if drug absorbed into lower or distal segment of rectum Typically increased absorption</td>
</tr>
<tr>
<td><strong>Intramuscular Absorption</strong></td>
<td>Perfusion, muscle mass, and activity</td>
<td>Usually decreased Increased capillary density in neonatal muscle</td>
<td>Decreased rate of absorption due to decreased cardiac output Potential local trauma</td>
</tr>
<tr>
<td><strong>Transdermal Absorption</strong></td>
<td>Surface area-to weight ratio</td>
<td>Increased</td>
<td>Increased absorption</td>
</tr>
<tr>
<td></td>
<td>Stratum corneum</td>
<td>Incompletely formed</td>
<td>Increased absorption</td>
</tr>
<tr>
<td></td>
<td>Vasomotor control</td>
<td>Immature</td>
<td>Increased absorption</td>
</tr>
<tr>
<td><strong>Inhalation</strong></td>
<td>Mucosal permeability</td>
<td>Increased</td>
<td>Systemic exposure</td>
</tr>
<tr>
<td><strong>Distribution</strong></td>
<td>Total body water</td>
<td>Increased volume of distribution</td>
<td>Reduced peak and threshold concentrations at weight dosing</td>
</tr>
<tr>
<td></td>
<td>Extracellular water</td>
<td>Increased</td>
<td>Further expands volume of distribution</td>
</tr>
<tr>
<td></td>
<td>Body fat composition</td>
<td>1% of adult level in preterm and 15% in term infants</td>
<td>Lower lipophilic drug disposition</td>
</tr>
<tr>
<td><strong>Blood-brain Barrier</strong></td>
<td>Permeable barrier</td>
<td>Immature</td>
<td>Increased potential permeability</td>
</tr>
<tr>
<td><strong>Protein Binding</strong></td>
<td>Plasma proteins</td>
<td>Decreased</td>
<td>Increased free/unbound drug available to receptors</td>
</tr>
<tr>
<td><strong>Metabolism</strong></td>
<td>Biotransformation primarily involving hepatic enzymes</td>
<td>Decreased</td>
<td>Drug dependent: renders some drugs more active and some less active; often affects clearance</td>
</tr>
<tr>
<td><strong>Hepatic Blood Flow</strong></td>
<td>Extraction or removal of active drug by metabolism</td>
<td>Increased cardiac output to liver increases hepatic flow</td>
<td>Increased clearance of drugs with high intrinsic hepatic clearance</td>
</tr>
<tr>
<td><strong>Renal Elimination</strong></td>
<td>Glomerular filtration</td>
<td>Dependent on renal blood flow; reduced in premature infants; reaches adult levels by two years of age</td>
<td>Most drugs have delayed clearance with increased half-life elimination with individual variability</td>
</tr>
<tr>
<td></td>
<td>Tubular secretion</td>
<td>Reduced active secretion</td>
<td>Delayed excretion and prolonged half-life</td>
</tr>
<tr>
<td></td>
<td>Tubular reabsorption</td>
<td>Reduced</td>
<td>Dependent on renal blood flow, glomerular filtration rate, urine output, urine pH, and tubular secretion</td>
</tr>
<tr>
<td><strong>Clearance</strong></td>
<td>Multisystem function</td>
<td>Reduced</td>
<td>Accumulation</td>
</tr>
</tbody>
</table>

Infant body composition can affect drug distribution. Due to the increased water composition and decreased fat composition, water soluble drugs (e.g. aminoglycosides) have increased volume of distribution, while lipophilic medications (e.g., LORazepam) have a lower volume of distribution. Serum albumin and protein concentrations are decreased in neonates. Therefore, drug binding to plasma proteins will be decreased, resulting in increased free drug (e.g., phenytoin). Some medications (e.g.,...
ceftriaxone, sulfamethoxazole) displace bilirubin from protein binding sites. Neonates are unable to adequately excrete bilirubin, resulting in elevated bilirubin levels. Due to the increased permeability of the blood-brain barrier, neonates are at risk for accumulation of bilirubin in the brain, known as kernicterus.

Preservative free products should be used whenever possible. Preservatives, such as benzyl alcohol and propylene glycol, have been associated with serious side effects, including gasping syndrome, lactic acidosis, seizures, and death. Gasping syndrome includes symptoms of metabolic acidosis that progresses to respiratory distress, gasping respirations, and possibly death.

Immunizations may be given according to standardized schedules even in premature infants, although benefits and burdens must be weighed depending on patient’s life expectancy. Hepatitis B vaccine is more effective if given once patients reach 2,000 g, but should not be delayed beyond 30 days of life.  

Effective symptom management in neonates can be more challenging due to different pharmacokinetic properties. Utilizing some of the above principles can help guide thought processes. As always, managing symptoms in neonates should be patient-specific.

Key References

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The Post-Mortem Conference following the Death of a Fetus or Neonate: A Step Closer to Closure

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The death of a fetus or neonate creates a profound sense of grief, anxiety, guilt, and hopelessness for families experiencing these losses. At the time of their loss, most families are so enveloped in their own grief that they cannot make sense of any sophisticated medical discussions regarding the cause of the death of their baby. [Henceforth in this article, I will use the term “baby” to refer to the “fetus” or the “neonate”.] It is generally better to postpone such detailed discussions for a time weeks to months in the future. In addition, if parents have decided to have an autopsy performed on their loved one, these results may also take weeks to months to become available, and could also be discussed at the time of the post-mortem conference.

The health care professional's preparation for the post-mortem conference begins at the time of the death of the baby. Parents who desire that their baby have an autopsy should be reminded that the principal reason to do the autopsy is to find out more information about why their baby died in order to help them understand and come to closure. A secondary reason to perform an autopsy is that autopsy results might help the health care providers or medical science in general to know more about that particular condition. Autopsy rates have dropped to less than 10% in recent years, which may mean that fewer families may have the information they need to help them come to closure. Families should also be informed that autopsy results generally take weeks or months to return, because the pathology doctors have to fix and stain the tissues on microscope slides, and then examine them under the microscope, long after the baby's remains have been laid to rest. A patient can still be buried or cremated while his or her autopsy results are pending. When told that the autopsy results will probably be available in 2-3 months, many families misunderstand, hearing “2-3 days” or “2-3 weeks” instead. Therefore, I generally let families know that I will contact them around some certain event on the calendar (middle of the summer, or on Valentine's Day, etc.) that is timed most conveniently to mark this time interval. Even if the autopsy results are not available on the date that I contact the family, families appreciate a telephone call or a greeting card asking how they are doing and letting them know that I am thinking of them and their little one. During this contact, I let them know that I, too, am anticipating the autopsy results soon and that I will call them to arrange our conference as soon as we get the results. This preliminary contact with the family may be an opportunity to address special concerns that they may have, or an opportunity to acquire specific information to answer their particular questions by the time of the post-mortem conference.

Parents who decline having an autopsy performed on their baby still need several weeks or months for the grieving process before the post-mortem conference. I ask them if they would like me to call them (giving a specific time point on the calendar) to see how they’re doing and to talk about their baby’s illness, medical care, etc. I provide all parents with a copy of my business card, in case they need to reach me before I had otherwise planned to call them. Each parent needs to receive a copy of my business card. The death of a baby is a stressful event that severely taxes some relationships, and there is no guarantee that the parents will still be together at the time of the post-mortem conference. Therefore, they should each have my contact information. My business card is like their lifeline to making some sense of the situation. People grieve and heal in different ways (some requiring more contact with the baby’s health care providers and some, less) and, if one parent feels the need to call me, while the other doesn’t, he/she should have that opportunity.

Once you, the health care provider, have received the final autopsy report, you should read it carefully for errors (Correct patient? Correct sex? Correct weight? Correct dates of birth and death?) before calling the family to schedule the conference.
Many parents are able to come back to the hospital for a face-to-face meeting. In this meeting, they may hope and expect to meet with the attending physician, a primary nurse, or nurses or doctors who cared for the baby in his/her final hours. It is worthwhile to ask families if they would like anyone in particular to be present at the post-mortem conference. With enough advance notice, this can usually be arranged. Coming back to the hospital where their baby died and seeing people who cared for their baby is certain to bring back terrifying memories for these parents. We must recognize their courage in even showing up at all. We can protect these parents from having such an agonizing experience during the post-mortem conference by arranging to meet with them in a conference room not directly associated with the patient care area where the death occurred. Nevertheless, the post-mortem experience will be an emotional time for them and I recommend having tissues and drinking water available for grieving parents. The physical set-up of the room is also important. When possible, it is preferable to have the post-mortem conference in a private room which is set up like a family room, with couches and soft chairs arranged in an informal circle, rather than in a classroom or a board room where families may feel that they are on display or being interrogated.

Some parents prefer to have the post-mortem conference via telephone. Some simply cannot bring themselves to set foot in the hospital again, because it elicits such strong and unpleasant memories. Some state that difficulties with transportation prevent them from attending a post-mortem conference at the hospital. Even though the social worker may be able to arrange free transportation for the family to attend the post-mortem conference, generally these families turn down the offer for free transportation, often because they also are fearful about returning to the location of their baby's death. We can arrange for a post-mortem conference to occur via telephone. If the parents cannot be together on a speaker phone at the time of the post-mortem conference, arrangements can be made to do the conference by means of a conference call, at a mutually agreed-upon date and time. A week or so before the post-mortem conference, if the family agrees, I will send each parent a copy of the autopsy report. Since autopsy reports are generally many pages long with much description, in medical terms, of normal anatomy, before I mail the autopsy reports to them, I highlight the items of interest regarding their particular baby. On the day of the post-mortem conference, I will discuss the highlighted issues with them in great depth and will also offer to review the non-highlighted normal anatomy. In addition to discussing the autopsy report, the post-mortem conference is an appropriate time to discuss the baby's disease, disease-progression, and details of medical management. For families that declined an autopsy, these topics should be discussed as well. We should make ourselves available at the time of the post-mortem conference, and beyond, to answer any further questions that the parents may have.

The post-mortem conference is one opportunity the health care professionals may have to assess how the family is handling the myriad of emotions associated with their loss. I generally let families know which resources are available for families who have suffered this type of loss, and, depending on my observations of the family, may strongly suggest that they seek these additional supports.

Families often want to know if the baby suffered at the end. I try to answer this question honestly, based on any pain scoring that was done, or based on my observations of the baby while he/she was alive. I also let the families know what medications or interventions were being used to help control the baby's pain. If the family was present at the time of the death of the baby, I let them know that their voices, touch, and love were likely familiar and soothing to the baby.

Throughout the post-mortem conference, referring to the baby by his/her given name shows respect for the baby as an individual. As mentioned in the first sentence of this article, there is a fair amount of (usually maternal) guilt involved in the death of a baby. The death of a baby is, in fact, very seldom the mother's fault. Additionally, uninformed family members may place the blame for the baby's death on the mother. Therefore, in each post-mortem conference, I look at the mother directly and say, “There is nothing you did and nothing you neglected to do that made your baby die.” I make sure that the other family members in the room hear and acknowledge this statement.

Finally, with an eye on the future, parents want to know if something like this will happen again with a subsequent baby. Generally, such situations are not recurrent, but occasionally, a genetic condition will
be carried within the family, creating a risk that a similar situation may happen again. If this is the case, genetics consultation for parental genetic testing, and comparison with the baby's genetic composition, if available, is appropriate. In this situation, completing a genetic work-up and formulating a plan to have a healthy baby in any subsequent pregnancy would be warranted prior to conception next time. The health care provider meeting with the family during the post-mortem conference and giving guidance to them in the future can be a most helpful liaison between high-risk bereaved families and the health care system.

The post-mortem conference, and the relationship formed between the health care professionals and the grieving family, provides us the opportunity: to assist the family in understanding the cause of their baby's death, to understand what the baby might have been experiencing, to assist the family in seeking appropriate supports, and to plan for the future. Often, the relationship between the family and the health care professionals endures over time and fosters further healing and closure for the family.
PERINATAL PALLIATIVE CARE/HOSPICE-RELATED RESOURCES

Compiled by Ann Fitzsimons, BS, MBA
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Outlined below is a listing of some of the resources available to parents and professionals on the topic of perinatal hospice and palliative care. However, it should be noted that one of the most comprehensive resources for families expecting a baby who may die before or shortly after birth, and the professionals who care for them, is the Perinatal Hospice website—www.perinatalhospice.org—a comprehensive site inclusive of perinatal resources for parents and providers (i.e., caregivers).

Listed here are websites for parents, and separately for providers/professionals; Toolkits; sample birth plans; a link to a perinatal photography resource; books for parents; books for siblings; and relevant DVD’s.

Websites for Parents

Perinatal Hospice.Org (www.perinatalhospice.org)
- A comprehensive clearinghouse of information about perinatal hospice and palliative care for parents and providers
- Resources include a listing of perinatal hospice/palliative care programs in the U.S. and internationally, medical journal articles, professional resources for providers, resources for families, sample birth plans, among others.

Share Pregnancy and Infant Loss Support, Inc. (www.nationalshare.org)
- An organization whose primary purpose is to provide support toward positive resolution of grief experienced at the time of, or following, the death of a baby.
- A provider of information, education, and resources on the needs and rights of bereaved parents and siblings to members of the community and providers in their supportive roles to the family.

Websites for Providers/Healthcare Professionals

End-of-Life Nursing Education Consortium (ELNEC)
(https://www.reliasacademy.com/rls/browse/productDetailSingleSku.jsp?productid=c281198)
- Perinatal and Neonatal Palliative Care Training module which provides an overview of the unique aspects and issues related to providing this kind of care.

Gunderson Lutheran Bereavement Services (www.bereavementservices.org or berservs@gundluth.org)
- Bereavement education, consultation, and support materials, inclusive of its Resolve Through Sharing (RTS) program, one of the first professional perinatal bereavement education programs.
- Resources include a Perinatal Palliative Care Toolkit, family brochures, conferences/workshops/webinars, publications, and catalog of resources for bereaved parents and professionals.

Hospice and Palliative Nurses Association (HPNA) (http://advancingexpertcare.org/cplc/)
- Certification in Perinatal Loss Care (CPLC®) consists of an examination designed for health professionals (i.e., RN, physician, psychologist, counselor, child life specialist, social worker or chaplain) who provide care for those families experiencing perinatal loss and/or bereavement support for these types of losses.
Certification is earned through the Hospice & Palliative Certification Center.

Hospice and Palliative Nurses Association (HPNA) ([https://nurseslearning.com/syllabus.cfm?CourseKey=7266](https://nurseslearning.com/syllabus.cfm?CourseKey=7266))
- Offers an interactive ethics module called, “When Hello Means Goodbye: An Exploration into Perinatal Palliative Care,” for CE credit.
- Course objectives include being able to apply ethical concepts to the care of a family receiving perinatal palliative care, learning to practice being a patient advocate, and examining communication options when a patient requests care that is different from what the physician recommends.

- A free e-course on Perinatal Palliative Care designed to enhance the knowledge and confidence of health professionals providing the delivery of care to infants and their families prenatally through and after the birth of the baby.
- Course modules include education on palliative care and its delivery, creating memories, case studies, resolving conflicts about end-of-life decisions, and organ donation.

- This is an evidence-based Neonatal and Perinatal Palliative Care e-course offered for CE/CME credit for counselors, nurses, physicians.
- Dr. Brian Carter is the faculty for this 1.5 hour e-course that has as its objectives to help the learner identify the frequency of prenatal detection of fetal anomalies in the U.S. that may shape PPC decisions for patients and providers, list three common end-of-life symptoms in neonatal end-of-life care, and discuss key components for talking with parents about the redirection of care goals for their infant.

Perinatal Hospice.Org ([www.perinatalhospice.org](http://www.perinatalhospice.org))
- Also offers resources for professionals. See listing above.

Pregnancy Loss and Infant Death Alliance (PLIDA) ([www.plida.org](http://www.plida.org))
- A professional organization dedicated to providing support to parents grieving the death of their baby or babies during pregnancy, delivery, or infancy.
- Their mission is to support health care practitioners and parent-advocates in their efforts to improve care for families who experience the death of a baby during pregnancy, birth, or infancy through resource development, position statements, publishing of best practice guidelines, among others.

**Toolkits**

**A Perinatal Pathway for Babies with Palliative Care Needs by Together for Short Lives (U.K.)** ([http://www.togetherforshortlives.org.uk/professionals/resources/11598_perinatal_pathway_for_babies_with_palliative_care_needs](http://www.togetherforshortlives.org.uk/professionals/resources/11598_perinatal_pathway_for_babies_with_palliative_care_needs))
- A toolkit developed to support providers in supporting families with seriously-ill babies to the best experience possible, regardless of the outcome for the baby.
- Pathway is available for a free download at this link.

- This is RTS’s Blueprint for a Perinatal Palliative Care Program® Toolkit which is available as a resource for those looking to develop a Perinatal Palliative Care Program at their facility.
- The kit is divided into four sections including how to organize the work, communication and
TPS Perinatal Palliative Care and End-of-Life Web-Based Toolkit (Texas Pediatric Society Committee on Fetus and Newborn
[https://txpeds.org/palliative-care-toolkit](https://txpeds.org/palliative-care-toolkit)
- Designed to assist physicians in navigating the various topics associated with providing palliative care for babies/infants.
- The toolkit is comprised of many sections, including: Structure & Processes of Care; Physical, Psychological and Social Aspects of Care; Spiritual/Religious/Existential Aspects of Care; Cultural Aspects of Care; Ethical/Legal Aspects of Care, among others.
- The toolkit is available for free reference on this website.

**Birth Plans**

A sampling of birth plans, some in Spanish, are available through the Perinatal Hospice website at this link (Note: Scroll down to Birth Plans): [http://www.perinatalhospice.org/resources-for-parents.html](http://www.perinatalhospice.org/resources-for-parents.html).

We also refer you to a previous issue of this ChiPPS e-Journal #30 on Perinatal Palliative and Hospice Care published in February, 2013, for two articles by Dr. Suzanne Toce, one on the Components of a Birth Plan when the Baby has a Life-Threatening Condition (p. 34) and one on the Components of a Neonatal Advance Care Plan (p. 36). [https://www.nhpco.org/sites/default/files/public/ChiPPS/ChiPPS_February-2013_Issue-30.pdf](https://www.nhpco.org/sites/default/files/public/ChiPPS/ChiPPS_February-2013_Issue-30.pdf)

**Perinatal Photography**

- Now I Lay Me Down to Sleep is an organization of trained and educated professional photographers who provide heirloom photos to families facing the loss of a baby.
  - [https://www.nowilaymedowntosleep.org/](https://www.nowilaymedowntosleep.org/)

**Books for Parents**

**A Gift of Time: Continuing Your Pregnancy When Your Baby’s Life is Expected to be Brief**
By Amy Kuebelbeck and Deborah Davis (2010)
A practical and supportive guide for parents choosing to continue with their pregnancy despite knowing their unborn child will likely die before or shortly after birth, including suggestions for parents and caregivers. Families’ stories are included to offer inspiration and reassurance on this journey for these families.

By Tim Nelson
Written for men experiencing the death of an infant child through miscarriage, stillbirth, or early infant death, as a guide for navigating those early hours and days after the baby’s death with the medical team, their partner, and other surviving children.

By Ingrid Kohn, MSW, and Perry-Lynn Moffitt
A positive first step for parents and families grieving the loss of a baby during pregnancy, this book offers emotional and practical support to help families find healing from their grief and look forward with hope.

**An Exact Replica of a Figment of My Imagination: A Memoir (2010)**
By Elizabeth McCracken
A mom shares her experience of having her baby boy die in her ninth month of pregnancy with warmth and humor as she opens up about what her grief and bereavement were like after this precious loss.

**Conversations in Perinatal, Neonatal, and Pediatric Palliative Care (2017)**
Written to help readers truly experience what the world of children with serious illness is like, this book is a comprehensive look at the issues families face when a baby or child is seriously-ill. This publication also includes insights on establishing and sustaining pediatric palliative care programs, including perinatal and neonatal care. Note: This item can only be ordered from the Hospice and Palliative Nurses Association https://www.hpna.org/HPNA_Item_Details.aspx?ItemNo=978-1-934654-36-1

**Couple Communication After a Baby Dies: Differing Perspectives (2008)**  
**By Sherokee Ilse and Tim Nelson**  
An honest, in-depth look at how the loss of a baby can impact the spousal relationship with strong emphasis on offering hope, encouragement, and promotion of healthy, open communication between the couple. Other couples’ stories help to normalize the parents’ feelings while questions and conversation starters prompt the couples to talk to one another in private or in group sessions.

**Empty Arms: Coping with Miscarriage, Stillbirth and Infant Death (20th Edition 2015)**  
**By Sherokee Ilse**  
Written by a bereaved mom for helping families survive the first hours after a baby’s death and beyond. It is written to provide guidance in making decisions immediately after the baby’s death and provides suggestions for caregivers as they struggle to support the family. Note: Also available in Spanish as Brazos Vacios.

**Empty Cradle, Broken Heart: Surviving the Death of Your Baby (2016)**  
**By Deborah L. Davis**  
This book offers encouragement for grieving parents after the loss of a baby or infant, while making suggestions for coping with the pain and feelings often associated with a loss of this nature. This new edition also addresses questions of aggressive medical treatment for these babies, as well as issues fathers face during these baby losses. The family’s medical team, as well as family and friends, will also gain insight on how to support these parents in this guide.

**Grieving the Child I Never Knew: A Devotional for Comfort in the Loss of Your Unborn or Newly Born Child (2015)**  
**By Kathe Wunnenberg**  
Written by a mother who experienced three miscarriages and the death of an infant son, this book will provide encouragement and comfort for mothers encountering the loss of their baby through miscarriage, tubal pregnancy, stillbirth, or early infant death.

**Healing Your Grieving Heart after Stillbirth (2013)**  
**By Alan D. Wolfelt**  
A compassionate look at the common feelings families experience after the death of a stillborn baby—shock, anger, guilt, and sadness, as well as suggestions for remembering the baby and ways for the whole family to work towards healing.

**Little Footprints (1989)**  
**By Dorothy Ferguson**  
A memory booklet for families who have had a baby die due to stillbirth or who died shortly after birth. Includes a journal and pages with pockets for memorial keepsakes of their baby like locks of hair, name bands, and cards. Note: Also available in Spanish as Sus Pequenas Huellas.

**I Will Carry You: The Sacred Dance of Grief and Joy (2011)**  
**By Angie Smith**  
The true story of a family told their fourth daughter was “incompatible with life” after a pregnancy ultrasound. Despite being advised to terminate the pregnancy, the family chose to carry this child even while knowing the outcome. A powerful story of a parent losing a child which touched many as the mom journaled about this journey to the death of their baby.
Miscarriage (1983)
By Joy and Marv Johnson
This book is written for parents and families who have experienced the loss of a baby through miscarriage. It offers suggestions and emotional support on how to cope with this loss. Note: Also available in Spanish as Aborto Espontaneo.

Miscarriage – A Man’s Book (1995)
By Rick Wheat
Written by a dad and husband whose wife experienced a miscarriage, the author shares what it is like for a man to experience this kind of baby loss feeling everything from grief to depression to anger, and so much more.

Planning a Precious Goodbye: Following Miscarriage, Stillbirth, SIDS or Infant Death (2016)
By Cherokee Ilse & Susan Erling Martinez
This resource is for families whose baby or infant has died which helps to guide these parents through the important steps of birth/death announcements, hospital release forms, autopsies, contacting the funeral home, and planning a memorial service. It includes readings, poems, songs, and Scripture verses, as well as instructions for writing an obituary for the baby.

By Sharon N. Covington
This booklet is written for parents who have lose a baby during pregnancy, labor, or shortly after birth with the intent of helping them know what to do after the baby’s death through meaning-making like memorial legacy activities by which to remember the baby. It can also provide insight for those supporting the family who are trying to understand how to help them.

Still: A Collection of Honest Artwork and Writings from the Heart of a Grieving Mother (2010)
By Stephanie Paige Cole
A bereaved mom’s introspective look at that first dark year after the death of her daughter one week after her pregnancy due date. It was written to help bring a voice to this unspeakable loss for families and to provide companionship to these families who often feel so alone and isolated after baby losses like these.

Stillbirth, Yet Still Born. Grieving and Honoring Your Precious Baby (2014)
By Deborah L. Davis
A short book tailored to provide support for parents immediately after the death of baby who dies before birth. It addresses the unique aspects of grief from a baby born still and provides comfort and suggestions for acknowledging and honoring the baby’s short, but precious, life.

They Were Still Born: Personal Stories About Stillbirth (2014)
By Janet C. Atlas
Written by a bereaved mom who had a daughter born still, this collection of essays shares firsthand what parents—both moms and dads—go through when they experience this type of baby loss. It also includes sections which address the medical questions parents have when they have a baby born still, as well as inspiring suggestions for ways to honor and remember these babies’ short lives.

This Little While (2000)
By Joy and Dr. S. M. Johnson
A booklet written for parents who are or have experienced the death of a stillborn baby or a very young infant. The booklet provides guidance on how to deal with hearing the bad news, while guiding parents to do some of the important memorial rituals before leaving the hospital. Also includes sample birth/death announcements and supportive resources. Note: Also available in Spanish as Ese Momentito.
Three Minus One: Stories of Parents Love and Loss (2014)
By Sean Hannish
A collection of intimate stories and artwork by and from parents who have lost a child before birth or as a neonate, this book was the inspiration for the film “Return to Zero” (see description elsewhere in this compilation). Through memoirs, stories, poems, paintings, and photography, parents who have suffered a baby loss offer insight into their experiences to offer hope and healing to others who may have or who are experiencing a similar loss.

by Amy Kuebelbeck
A well-known resource for families in the situation of having to make decisions about their unborn baby’s health and medical conditions while they are still in the womb. A true story of a family facing news their unborn baby had an incurable heart condition and their life-changing journey as a result of that news. Also addresses tough issues of the role of heroic medicine, attitudes and practices regarding pregnancy/infant loss, and the ethical and moral dilemmas advanced prenatal testing can cause.

When Your Baby Dies – Through Miscarriage or Stillbirth (2002)
By Louis Gamino & Ann Cooney
A book with separate sections for dads, moms, and grandparents, this book explores the grief associated with both miscarriages and stillbirths, while offering comfort to those mourning the loss of the baby.

By Paul Kirk and Pat Schwiebert
A sensitive guide for parents at/shortly after the baby’s death to help prepared them for the short days ahead. Covers topics like collecting keepsakes, celebration of the baby’s short life, saying good-bye to the baby, among others.

Books for Siblings

No New Baby (1988)
By Marilyn Gryte
Written for siblings who have a baby brother or sister die before birth, this books helps the siblings explore their feelings and answers some of their most commonly asked questions when losses like this occur in families.

By Cathy Blanford
Written for a young child to help them understand when the family has had a baby die during pregnancy. Also focuses on helping the child process his/her feelings about the loss from a child perspective.

We Were Gonna have a Baby, But We Had an Angel Instead (2003)
By Pat Schwiebert
A book for preschoolers (2-5 years) to help them understand the loss of a baby during pregnancy in their family.

Where’s Jess: For Children Who Have a Brother or Sister Die (1982)
By Marvin Johnson
An often-recommended and used book by professionals when young children have a sibling die as an infant, this book deals with this loss for a sibling in easy-to-understand terms and a gentle tone helping them discuss their feelings and fears as a result of this loss.
**DVDs**

**Footprints on Our Hearts: Walking Through Grief After a Miscarriage, Stillbirth, or Newborn Death**
*By Paraclete Press (1997)*
A DVD of bereaved parents sharing their stories and experiences of losing their babies as a means of offering help for the guilt, helplessness, and sorrow others in similar experiences may be feeling. It offers suggestions for making meaning of the loss through legacy work like photos, naming the baby, journaling and memorial rituals. Also provides perspective on how men/women grieve differently and learning to live with the loss, among other relevant topics.

**Return to Zero (2014)**
*Producers: Sean Hannish, Paul Jaconi-Biery, Kelly Kahl*
A movie made based on the true story of a couple preparing for the arrival of their first child, only to find out that their baby son has died in the womb and that he will be stillborn. Available for purchase on Amazon.

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READERS’ CORNER

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Palliative care in the neonatal unit: Neonatal nursing staff perceptions of facilitators and barriers in a regional tertiary nursery.
Kilcullen, M. & Ireland, S. BMC Palliative Care 2017;16:32-43

Abstract:

BACKGROUND:

Neonatology has made significant advances in the last 30 years. Despite the advances in treatments, not all neonates survive and a palliative care model is required within the neonatal context. Previous research has focused on the barriers of palliative care provision. A holistic approach to enhancing palliative care provision should include identifying both facilitators and barriers. A strengths-based approach would allow barriers to be addressed while also enhancing facilitators. The current study qualitatively explored perceptions of neonatal nurses about facilitators and barriers to delivery of palliative care and also the impact of the region allocation of the unit.

METHODS:

The study was conducted at the Townsville Hospital, which is the only regional tertiary neonatal unit in Australia. Semi-structured interviews were conducted with a purposive sample of eight neonatal nurses. Thematic analysis of the data was conducted within a phenomenological framework.

RESULTS:

Six themes emerged regarding family support and staff factors that were perceived to support the provision of palliative care of a high quality. Staff factors included leadership, clinical knowledge, and morals, values, and beliefs. Family support factors included emotional support, communication, and practices within the unit. Five themes emerged from the data that were perceived to be barriers to providing quality palliative care. Staff perceived education, lack of privacy, isolation, staff characteristics, and systemic (policy and procedure) factors to impact upon palliative care provision. The regional location of the unit also presented unique facilitators and barriers to care.

CONCLUSIONS:

This study identified and explored facilitators and barriers in the delivery of quality palliative care for neonates in a regional tertiary setting. Themes identified suggested that a strengths-approach, which engages and amplifies facilitating factors while identified barriers are addressed or minimized, would be successful in supporting quality palliative care provision in the neonatal care setting. Study findings will be used to inform clinical education and practice.

Who is the audience for this information? Nurses will see particular benefit from this information, but all perinatal health care providers, as well as parents and family members will also benefit by understanding the process by which barriers and facilitators can be identified.
What is special about this article? There is limited information on this topic from the nurses' perspective. Focusing on both strengths and weaknesses (rather than the more usual weaknesses) of the current system of care allows a unit to move towards a higher quality of perinatal palliative care. Although this study is from Australia, most of the themes noted are very applicable to any location. “Systemic” barriers, i.e., policies, procedures, and physical limitations of the unit, are unique to each setting.

Where and how can I apply this information? The first step in enhancing an integrated model of perinatal palliative care is to understand the barriers and facilitators of quality perinatal palliative care. This should include input from multiple professions (i.e., nursing, medicine, ancillary staff, social worker, spiritual care, administrative staff, etc.) across many divisions and departments (i.e., OB, perinatology, pediatrics, neonatology, etc.), and across many sites of care (i.e., outpatient, inpatient, community setting, etc. This study provides a starting framework.

**Abstract:**

**Objective:**

Delivering prognostic information to families requires clinicians to forecast an infant’s illness course and future. We lack robust empirical data about how prognosis is shared and how that affects clinician/family concordance regarding infant outcomes.

**Study Design:**

Prospective audio recording of neonatal intensive care unit family conferences, immediately followed by parent/clinician surveys. Existing qualitative analysis frameworks were applied.

**Results:**

We analyzed 19 conferences. Most prognostic discussion targeted predicted infant functional needs, for example, medications or feeding. There was little discussion of how infant prognosis would affect infant/family quality of life. Prognostic framing was typically optimistic. Most parents left the conference believing their infant’s prognosis to be more optimistic than did clinicians.

**Conclusions:**

Clinician approach to prognostic disclosure in these audiotaped family conferences tended to be broad and optimistic, without detail regarding implications of infant health for infant/family quality of life. Families and clinicians left these conversations with little consensus about infant prognosis.

**Who** is the audience for this information? Health care providers and others involved in discussing prognosis with families of critically ill infants need to read this article. According to these data, we aren’t doing a particularly good job if the goal is to meet the parents’ need for accurate information about the quality and length of life, and range of potential outcomes including impact on the family.

**What** is special about this article? While small numbers of conversations with parents were recorded, these were actual NICU conversations and not anyone’s recollection of what was said. These data confirm that even accepting that predicting a prognosis is inherently inaccurate, there remains a parental bias toward being overly optimistic about the length and quality of life. The prognostic information provided was often vague and with inadequate detail, thus facilitating discordant views about prognosis. Interestingly, other research has supported the concept that families benefit from and desire as specific information as possible. The authors notably review aspects of the conversations that encouraged
concordance of understanding between the providers and the parents concerning their infant’s prognosis. One other interesting and helpful bit of information is that only 1/3 of parents raised the topic of prognosis, supporting the need for the clinicians to initiate the discussion. In cases where the clinicians were very pessimistic, thinking that the infant had a <25% chance of living without serious sequelae, they were twice as likely to be more optimistic in their discussion of prognosis. Discussion of the infant’s prognosis rarely included the potential impact on the family’s quality of life despite the fact that quality of life is one of parents’ most important concerns.

**Where and how can I apply this information?** Clinicians are challenged in the NICU to provide detailed prognostic information in the setting of uncertainty that is so common with critically ill infants. In other settings, tools such as “best case/worst case/most likely outcome” have shown some promise and deserve to be evaluated in the NICU setting. Although clinicians may think that they are skilled in delivering bad news, they clearly are often not. Providers should seek training that supports communicating accurate delivery of prognostic information. They need to understand that this facilitates rather than diminishes parental hopes. They can provide information on ranges of expected outcomes. Review of implications of potential disabilities allows the parents to be more prepared and engaged in decision-making, especially with decisions to limit life-prolonging treatment. Other potential strategies to improve delivery of prognostic information might include parent tools such as questions to ask and suggesting that parents summarize what was discussed to ensure concordance of understanding.

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This article addresses the topic of pain and symptom assessment and documentation in children with life-limiting, non-malignant conditions. It provides insight into gaps in pain recognition and reporting in this under-studied group.

This paper emerged from the CIHR-funded study, ―Charting the Territory‖ (Primary Investigators: Dr. Siden and Dr. Steele). As a site Primary Investigator (PI) at one of the two US participating sites (Children’s Hospitals & Clinics of Minnesota), Dr. Stefan Friedrichsdorf was particularly interested in exploring pain and symptom reporting and management in this population. We were delighted to have the opportunity through this large multi-site collaboration to explore the topic in a large sample of children with rarer conditions that we would not otherwise have access to.

The article takes a closer look at parents’ pain reporting upon enrollment into the study, and what was recorded by their health care team in the medical record. We looked at pain and symptom reporting, management, and patient/family characteristics. We were surprised by the sizable discrepancy between parents’ pain reporting and health care provider documentation in the medical record (over 60% of pain documentation was missed). It remains unclear whether this discrepancy might have been due to lack of thorough clinical assessment, documentation, or both.

Another interesting finding was that—despite the higher likelihood of neuropathic pain in these children—medications that treat this type of pain were underutilized (e.g., adjuvant analgesia gabapentin). This finding suggests more education and research may be needed around neuropathic pain management. Another important finding was that children facing rare, life-limiting conditions were sicker and reported more pain. Unfortunately, this finding is in line with previous research on health disparities in children.

Finally, children whose pain was recorded in the medical record were more likely to be enrolled in a palliative care program. Interpretation of direction of causality was difficult, and would be an interesting research topic to explore further. In other words, does being enrolled in a palliative care program mean better documentation of pain, or is referral to a palliative care program more likely if pain is reported?

This citation list and commentary are generated monthly by PedPalASCNET to collect new articles in pediatric palliative care research. To see past citation lists and expert commentaries visit our website.

Citation List


Albuquerque, S., Narciso, I., & Pereira, M. (2017). Dyadic coping mediates the relationship between
parents' grief and dyadic adjustment following the loss of a child. *Anxiety Stress Coping*, 1–14. https://doi.org/10.1080/10615806.2017.1363390


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.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics). Also, more palliative care resources are available at [www.nhpco.org/palliativecare](http://www.nhpco.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

**IDC 2018 Call for Proposals**

NHPCO seeks proposals from professionals designed to advance the knowledge, competence and performance of hospice and palliative care professionals. Proposals of the highest interest to conference planners will include attention to both adult and pediatric populations in relevant focus areas. NHPCO’s 2018 Interdisciplinary Conference will offer extensive and intensive intermediate and advanced educational sessions that will address these specific topic areas:

- Community-Based Palliative Care
- Interdisciplinary Team Leadership
- Medical Care
- Quality
- Regulatory
- Supportive Care (psychosocial, spiritual and bereavement)

**Presentation Proposal Deadline:** **Friday, December 15, 2017; 11:59 pm ET**

Submit here

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](http://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** now 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

- **Center to Advance Palliative Care**: Did you know there are new tools to support your program? CAPC is pleased to announce the launch of three new resources for pediatric programs.
  - **Pediatric Palliative Care Survey in the CAPC National Registry**: Submit your program data now to generate individualized performance reports on program structure and operations, as well as comparisons to other pediatric palliative care programs. CAPC membership is not required.
  - **The Pediatric Palliative Care Field Guide**: A catalog of field-wide program development tools, support sources for field research, and an updated value statement to help programs make the case for pediatric palliative care resources.
  - **The CAPC Pediatric Palliative Care Toolkit**: A collection of new, practical tools and technical assistance for pediatric palliative care programs developed by leaders and experts across the country. Available to members now in CAPC Central.


- Three Years ago Holland Bloorview Kids Rehabilitation Hospital launched the Chronic Pain Assessment Toolbox for Children with Disabilities. The Toolbox has received over 6000 downloads to date! Since then three eLearning modules have been developed. The modules will introduce you to:
  1. Chronic pain in children with cerebral palsy and the development of the Toolbox
  2. The sections of the Toolbox and how to start with based on your needs
  3. A case study of a complex patient from one of our nurse practitioners, and how a chronic pain assessment tool supported her clinical examination.

  Check them out here: [http://hollandbloorview.ca/Toolbox](http://hollandbloorview.ca/Toolbox)

3. **Pediatric Hospice and Palliative Care Training**:

   - **HPCANYS 2-Day Interdisciplinary Pediatric Palliative Care Training Unique to New York**: The interdisciplinary team approach for both the child and family is what sets an excellent pediatric palliative care program apart. This training will focus on how disciplines overlap and support each other to provide optimum care for children at end of life. HPCANYS’ Pediatric Palliative Care training recognizes that all team members are an important part of the Plan of Care and each team member has something valuable to contribute.

   November 16-17, 2017
   8:30am—5:00pm
   The Sagamore
   110 Sagamore Rd.
Pediatric Hospice and Palliative Care: Advances and Innovations (Pedi-Innovate):
This summer pediatrics course will be a forum for interdisciplinary healthcare professionals and others with an interest in pediatric palliative care to deepen their knowledge and understanding of this nascent and rapidly-evolving field.
Through this course, we aim to advance pediatrics in hospice and palliative care for children with serious illness, thereby optimizing their quality of life, regardless of treatment course or illness trajectory. Learners will improve their knowledge, competence, and change their performance, leading over time to enhanced patient outcomes.
August 9-11, 2018
Minneapolis, MN
http://aahpm.org/meetings/pediatrics-course

4. Journal / News Articles

- Many kids dying of cancer get intense care at end of life: “With the right information and support for parents and families, many children who die in a hospital might be able to die at home instead” Read more here

- Disney, Pixar Movies Offer a Chance to Talk to Your Kids About Death: Researchers studied 57 Disney and Pixar movies for their research, which included 71 character deaths. They came across four themes to focus end-of-life discussions with children. Read more here

- Special teddy bears help families of pediatric hospice patient: A mother is keeping her son’s legacy alive by gifting teddy bears to families who have lost children and ones in hospice care. Read more here

5. Subjects and Contributors for Future Issues of This E-Journal. For upcoming E-Journal issues, we plan to address issues related to: Hospice and Bereavement for Crisis Situations, and Caring for Diverse Families and Populations. 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 Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

6. Reader’s Corner. Our Reader’s Corner columns provide brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric hospice and palliative care, but that may not be known to readers. We welcome suggestions for publications to include in our Reader’s Corner and/or summaries and comments on such articles. Please send suggestions to Christy Torkildson at christytork@gmail.com.

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