ChiPPS Pediatric Palliative Care Newsletter
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Issue Topic: Perinatal Palliative and Hospice Care

Welcome to the thirtieth issue of the ChiPPS electronic newsletter. This issue of our e-newsletter offers a PDF collection of articles that explore some issues related to providing perinatal palliative and hospice care to newborns and their families. Our goal in this issue is to promote reflection and involvement in palliative and hospice care when they are applied to life and death at the earliest moments of a child's existence. This is a developing area in pediatric palliative and hospice care, but it is one that deserves attention from readers of this newsletter and one for which many can make important contributions.

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

Comments about the activities of ChiPPS, its E-newsletter Workgroup, or this issue of the newsletter are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues of this newsletter. Please contact Christy at christytork@gmail.com or Maureen at Horgan.Maureen@gmail.com.
Issue #30: Perinatal Palliative and Hospice Care
(Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.)

The Thanksgiving Tree  p. 5
Scott Newport
Scott recalls nurturing a tree left for the trash that was retrieved by his wife and the parallel of this hopeful experience with that of nurturing his son Evan who was born with a life-threatening condition almost a year after planting that special tree.

A Cold Wave Made Warm  p. 7
Sandy White
Elizabeth’s mother paints a picture in her prose of her family’s journey with the Community PedsCare team from the time of learning about Elizabeth’s Trisomy 13 diagnosis in utero to her death 47 days after birth at home. The team assured Sandy and her family that they “were not going to be alone and would be OK.”

Eden’s Journey  p. 10
Maureen Pronschinske
“…you are going down a road that is unfamiliar to you.” With these memorable words, Maureen’s midwife informed her following an ultrasound that her baby had a life-threatening condition and might not survive birth. Maureen shares Eden’s story and insights about what caregivers and family and friends offered that was supportive throughout the pregnancy and in Eden’s 11 days of life.

A Gift of Time: Continuing a Pregnancy when a Baby’s Life is Expected to be Brief  p. 13
Amy Kuebelbeck
Amy Kuebelbeck provides the reader with an overview of the history and current state of perinatal hospice in the United States and some new language when referencing perinatal hospice care. She describes the care as “a beautiful and practical response to one of the most heartbreaking challenges of prenatal testing.” She reports that what might be called “hospice in the womb” is a growing phenomenon that increasingly more families are researching and choosing.

Rights of Parents When a Baby Dies: Choices or Mandates  p. 17
Catherine Lammert, RN
Catherine Lammert reminds providers that “the most vital part of decision-making is affected by the way caregivers present options.” In her article and in the lists of rights that follow, Catherine explains that these guidelines have been developed and/or adapted by Share Pregnancy and Infant Loss Support, Inc., with direct input from children and adults who have had a family death due to miscarriage or infant death. She provides thoughtful and practical suggestions to ensure the entire family is treated with respect and dignity. The rights serve as guidelines that are outlined for each family member honoring the unique roles that mother, father, siblings and other important family members hold.

Rights of Parents When a Baby Dies  p. 23
Rights of Parents Whose Baby Dies Very Early in Pregnancy  p. 24
Rights of the Baby  p. 25
Rights of Children When a Sibling Dies  p. 25
The Benefits of a Perinatal Palliative Care Program
Jill K. Wilke, BSN, RN
Each baby and family is unique and deserves an individualized plan of care. Resolve Through Sharing has been providing support to practitioners since the early 1980’s in designing standard operating procedures that are meant to be compassionately developed to meet the specific needs of each family who may be facing a shortened life for their baby. The article provides an overview of perinatal palliative care program design and information on how to attend upcoming programs to increase your skills in providing this type of care and starting such a program at an institution.

Community PedsCare Perinatal Program
Connie Bergh, MSH, RN, CHPPN
An overview of the Community PedsCare Program described earlier in this issue from a parental point of view by Elizabeth’s mother, Sandy White, is here provided by team clinician Connie Bergh. The program provides seamless care from community to hospital and stands as an exemplary model of care funded by community support.

Community PedsCare: Our Family Birthing Plan
This is one example of a Family Birthing Plan, an essential tool that can guide professionals and members of the family through a parent’s hopes and wishes for their baby’s birth process.

Components of a Birth Plan when the Baby has a Life-Threatening Condition
Suzanne S. Toce, MD
Dr. Toce offers specific language clinicians should consider when discussing the varied elements of a Birth Plan with parents of an baby with a life-threatening condition. The parent’s goals of care exist as the cornerstone of the planning process.

Components of a Neonatal Advance Care Plan
Suzanne S. Toce, MD
Dr. Toce further explores and provides an outline of issues that most families benefit from addressing when creating a neonatal advanced care plan. Components include review of medical issues and family support. Each plan should be tailored to the specific goals identified by the family.

What are the Options for Organ and Tissue Donation for a Baby with a Life-Threatening Diagnosis?
Jill K. Wilke, BSN, RN
The goal of this article is to explore whether organ and tissue donation is an option for families whose baby will die or has died. Jill Wilke acknowledges the opportunity for donation is rare for babies with life-threatening conditions, yet it remains an option that some parents may choose to explore for a variety of reasons.

Professional and Parental Resources for Prenatal/Perinatal Palliative & Hospice Care & into Bereavement
Compiled by Ann Fitzsimons, BS, MBA
Ann Fitzsimons offers a comprehensive gathering of resources related to Prenatal/Perinatal Palliative & Hospice Care.

Pediatric Palliative Care in Norway
Natasha Pedersen
Natasha Pedersen keeps her daughter Andrea’s legacy alive through advocacy to create palliative care treatment options for seriously ill children in Norway. Norway’s strong focus on
Curative medicine has been a barrier to palliative care services for children, but in 2011 the parliament decided that Norway should develop national guidelines for children with palliative care needs. It has been a slow and complex process that Natasha briefly outlines, one fueled in her efforts by a desire to honor Andrea.

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

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

Scott Newport
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It’s Thanksgiving weekend here in Michigan. The weather is cool. The sky is blue.

I am standing at the picture window, looking out at our front yard. And there it is—the small tree Penni and I planted three years ago. A few wilted-up leaves hang on, but soon they will be blown off. It's just a matter of time.

I remember the day Penni brought the tree home. As she pulled up in the driveway, I saw a big grin on her face. She got out of the car, producing the scraggily runt of a tree. She'd found it in a dumpster behind our local garden center. The tree's leaves were wilted, its roots were crowded, and the pot it was in was so very dry.

Being an optimist, I also began to smile. "We will bury it in good soil, fertilize it, and water it every day," I said. "We can save this tree." And Penni agreed. We decided to plant our little tree right in the center of our front yard for everyone to see.

Penni and I prepared the soil, lowered the tree into the ground, covered its roots with dirt, and watered it. As we worked, we talked about how beautiful our tree would be someday. We dreamed about the shade it would provide for our house once it was big and tall. We imagined hanging a rope swing from its limbs; lofting a tree house in its branches. We had big dreams for this little tree.

In the fall of that year, I decided to prune some of the branches to give it a great start for next spring. To be honest, our tree looked pretty sorry. As neighbors walked by, they'd see our tree and chuckle. "Why bother with that poor tree?" they'd whisper.

And I'd ask myself, "Why am I such an optimist? Why am I trying to save this tree?"

Thinking back to my early years, I remember playing basketball. I went to a small school and we had a terrible athletic program. In the years I went to school there, we never—not once—won a game. Not basketball. Not football. Not baseball. Nothing.

But I remember playing each and every game until the end as though we were going to win. Some of the guys would give up as they realized we'd lose, but I never did. As we'd walk off the court and I'd look up at the scoreboard, I was always surprised to learn that it wasn't even a close game.

I still don't know why I'm like this but I think it's a good characteristic.

Getting back to the tree, in the years since we planted our tree, it still does not look great. But I like that tree. I mean, it could have given up. Or I could have given up. But we didn't. Maybe someday that tree will be big and beautiful and the people passing by will admire it. But even if that doesn't happen, it's okay because there is much more to life than meets the eye. It's called hope. I like to hope. It's kinda what keeps me going and I think that's a good thing also.

My son Evan is 22 months old. When he was born, the doctors told us that he might not make it. They said, "He's not perfect. He has a lot of medical problems." After 252 days in the hospital, Penni and I
brought him home. We look at Evan and we see potential. We take him and love him and care for him—just like our little tree.

People look at Evan and you can see the look in their eyes—it's the same look they give the tree. But we put Evan right out there in front and show him off. We have hope that someday he will be big and strong just like the tree. But even if that doesn't happen, it's okay because life is full of imperfect things. If we give up, we lose. But if we hope, if we try to overcome, if we say, "We can do it," that's when we win.
A COLD WAVE MADE WARM

Sandy White
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Most parents are thrilled when they make it to the point in their pregnancy when they can go for the sonogram to see if they are expecting a girl or boy, and if it is healthy. We were expecting our second child and had arrived for this exciting event. It all changed when we did not see the cute button nose on our daughter, but instead an extension from it. My first thought was “we can have surgery to correct that.” I knew it would be an enormous event in our life but that it was doable and there was hope. It was when the nurse conducting the sonogram brought the doctor in and he said, “we have some concerns” that my heart froze.

We would soon find out that our daughter had Trisome 13, the birth defect consisting of a third chromosome on the thirteenth pair. As it was put to me, this was a syndrome where the brain forgets to tell the body to breathe. All I remember when we were given this news was that a giant, cold wave washed over me, like waves of freezing, cold water at the beach. I simply froze. My husband was with me, and we both just looked at each other. He took my hand and squeezed it while saying to me “I love you and we will get through this.” I did not know how we would but I believed him.

We had a meeting with my gynecologist afterward and made a few difficult decisions. My doctor let us know he was going to make a call to Dr. Kelly Komatz of Community PedsCare of Hospice, which he did. I did not know who Dr. Komatz was, or what Community PedsCare was. All I heard was that word “hospice,” and once again, I felt that freezing cold wave wash over. All I could think about was that our baby was going to die and there was nothing we could do to change it. It wasn’t fair, all those happy moms out in the waiting room, excited about their babies growing to soon be born and have chance at a full life. My little girl wasn’t going to have that.

In the next few days I saw our son’s pediatrician in the Target store. We said hello, and as I pulled her into the aisle with the macaroni and cheese, I broke down. I told her our prognosis and she hugged me the entire time. She too said she would call Dr. Komatz. I do not know how many people saw us in that store that day; all I remember was that I was afraid and did not know what to do.

Shortly after meeting our pediatrician, I received a call from Dr. Komatz and we set up a time for her to come meet us at our house. She was wonderful and very calming. Having her in our house helped me realize that we were not going to be alone and would be OK. There was no cold wave hitting me, but instead a feeling of warmth and hope in the midst of all the fear. Later that week a case was opened on our behalf, and we began the process of creating a birth plan to use at the hospital. We also met our nurse, Jenean, and case worker, Mary. Later we would meet our chaplain, Sharon. These women were extreme sources of comfort. They visited often, and over several meetings at our house we went over everything that would need to be considered before, during, and after our sweet daughter's birth. Through this entire time I was in awe of how much our team cared, not only about me as I was the mother, but also about my husband and our four-year-old son. These women obviously knew their trades as medical professionals but they also had something I did not expect...the human touch. They did not talk much about Elizabeth to our son, but instead brought him gifts of books and other items that made him feel included and important. I saw how this wasn’t just a job to them, it was a calling.

Our team from Community PedsCare made frequent visits to our home to make sure we were doing OK and to answer any questions we had. This is when the cold wave returned. I would be at work, the store,
anywhere really, and I would be struck frozen. I would weep with intensity that I did not know I had in me. The sorrow came from down deep; a place I did not know existed in me. People would tell me how this was all God’s plan. I did not want to hear about God’s plan, because it included taking our little girl from us. But I had our team and I could call them anytime I needed, which I did. What I did not realize at the time was that I was grieving. They all confirmed this, and the greatest thing they did for me at that time was listen. They explained to me that this was normal; it was part of accepting the situation and what it included in the end. Some people who we allowed to know about our daughter, who by now we’d named Elizabeth, felt they needed to have something comforting to say. All I needed was for someone to listen and let me cry. Our PedsCare team knew what to say, and what not to say. The thing they did for us when everyone else stayed away out of fear was they *stayed and they listened*. They helped us to complete our birth plan; they gave us literature to educate ourselves. They shared advice on how to be with people who were in denial of our daughter’s situation, and those who gave advice that was not helpful. Our team also brought us hugs, and smiles, sometimes tears to join with ours. But most of all, they brought genuine care and love. There were times when we felt completely alone as human beings, but we always knew our hospice team was near. This helped me to change my thoughts about God and be more accepting of his plan.

The day Elizabeth was born will probably be the day I have been the most afraid in my entire life. We did not know what to expect and anxiety was high. One comfort was that our birth plan had been entered into the hospital computer system, thanks to Dr. Komatz, and the staff was aware of our situation. Dr. Komatz was present at the birth of our daughter, and helped my husband with her the moment she came into the world. She and the rest of the team came to see us in our room often, and it brought much needed comfort.

Statistics show that half of Trisome 13 babies do not make it to birth. Those that are born do not live beyond a year. I remember my gynecologist coming in the last day we were in the hospital and saying “now the hard part starts.” Once again the cold wave washed over me. Our PedsCare team helped us come home and take care of our daughter. We’d had a meeting in our hospital room that last day before taking Elizabeth home and all arrangements were made. It was like watching a well-oiled machine do its work. They had supplies delivered: an air concentrator, air hoses, suction machine, everything we would need to care for our daughter. We were provided with feeding tubes, as Elizabeth had bi-lateral cleft pallet and would need to be gravity fed. When we came home, Dr. Komatz and our nurse, Jenean, showed us how to keep Elizabeth’s feeding tube taped down, how to feed our daughter, use the air hoses for “blow by’s,” and what to look for when they weren’t there. Never in my life did I imagine I’d need to learn how to put a feeding tube into my child in order for her to eat. My husband would tend to the “button” on her nose, as we described it to our son, keeping her clean and air passage clear. Our son was only four and really did not have much to do with his sister. He was afraid and we let him know it was OK. He only held her once, and again, that was OK.

Our PedsCare team came to our house to check on Elizabeth regularly during her 47 days of life. When they were not at our house they would call to see how we were doing and if we needed anything. Our
social worker, Mary, tried to see what financial aid we could qualify for since I was not working at the time. When we began to take Elizabeth to speech therapy to help her learn how to take a special bottle made for cleft palate, Mary arranged for payment of these appointments through charities for children. There were times I was unable to process in my mind how we would pay for things. Through donations from Community PedsCare we did not want for food or doctor bills that weren’t covered by insurance.

When Elizabeth’s health began to decline our team informed us of what to expect, and then they proceeded to stay with us. Once again we were not alone. Our nurse, Janine, had arranged for home nurses to come stay with us in the remaining few days so we would have help, to allow us to sleep, but mostly to ensure that if Elizabeth were to pass away that we would not be alone. We appreciated the help, although we did not sleep and still held our daughter the entire time. I was grateful for the added presence in the house though. On Elizabeth’s final day, our nurse, Jenean, came to stay with us. I don’t think we had ever cried as much as we did then. Jenean helped to make Elizabeth comfortable so we could hold her and watch her sleep. Jenean had taken photos of us with Elizabeth, with our permission, and for that I will always be grateful. After five years, it is still hard to see certain photos—in particular where we are consumed with grief; but we are grateful to have proof of how we were there at the beginning and at the end of our daughter’s life here on earth.

When Elizabeth passed away our team from Community PedsCare was there for us. Our well-oiled machine once again kicked into mode and helped us in every way. They called the funeral home to come collect our daughter. They made phone calls we were not able to. They cleared the machinery out of the way. They helped us clean and dress our child and take her hand and foot prints. We had not done these things yet. When it came time to explain to our son what had happened to Elizabeth, a child counselor from Community PedsCare helped us tell him the news. This organization later paid for our daughter’s burial from a fund they have specifically for this. Even after our daughter had left this world, Community PedsCare was there for us.

In the months following our daughter’s passing, we would call to see when our team would be in their office and go see them. These wonderful people had now become family to us. To this day we still keep in contact and attend functions created to remember our dear Elizabeth. Our Community PedsCare team was a true gift to us. Looking back, I do not know how we would have gotten through this journey with our daughter without our team. We would not have done anything differently, and my family will be forever grateful to them.
EDEN’S JOURNEY

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Our world was turned upside down on September 1, 2005. I was having what I assumed would be a routine ultrasound for my sixth pregnancy and I remember wishing the technician would hurry it along so I would be done by the time my husband finished taking our five kids to lunch. It didn’t occur to me there was something wrong until the technician said something to the effect of "I'm going to need the doctor to take a look at this." That is when my RN brain finally clicked on and I thought, “this can't be good.” Then, as I was sent over to my midwife appointment, I flipped through my packet of papers and there in large red letters it said, “Needs to see Dr. Peck, ASAP!” That is when I knew something was terribly wrong.

One of the first things my midwife said to me was, “Well, you are going down a road that is unfamiliar to you.” For some reason that phrase stuck in my head. And she was right. After carrying and delivering five healthy babies, I just expected things to be the same. Things weren’t supposed to go wrong; this wasn’t supposed to happen to me.

Fortunately, the high-risk OB MD (who wasn’t supposed to be in the clinic that day) happened to stop by and the staff was able to whisk me back for another ultrasound right then. The doctor described some of the problems he was seeing (hand deformity, heart deformity, brain deformity, etc.) and listed some of the possible syndromes that cause such things. I held it together pretty well during the ultrasound, but the minute I stepped into the parking lot I broke down. My husband saw me coming and practically carried me to the car.

The next thing I did was call my sister. She immediately packed up her kids and drove two hours to be with us. We spent the next few days researching every syndrome the doctor had mentioned. Those days were particularly difficult, not knowing what we were dealing with. Should we be planning for handicap accessibility, or should we be planning a funeral?

The next week we got our answer: a funeral. Our baby daughter, Eden Clarice, was diagnosed with Trisomy 18 and a hypoplastic left heart. If she made it to term and survived delivery, she was only expected to live for a few days.

This didn’t just feel like a new road, this felt like uncharted waters. Thankfully, we are blessed with a large supportive family, and the staff at our hospital was committed to making our birth experience the best it could be. Our Doctor of Neonatology was very familiar with Trisomy 18 babies and patiently answered our many questions. The staff went the extra mile and reserved the family birth room for us. However, even with all the extra care, Dennis and I felt very alone. Being pregnant and knowing your child will die is a difficult burden to bear.

With the help of caregivers we put a birth plan in place. My personal goal was that Eden would be born alive and we would all get a chance to hold her before she died. We also made plans to baptize her immediately and to take family photos. I requested the water birth room because I wanted Eden’s birth to be as normal and as much like her siblings’ births as possible. We also hoped we could take her home to die.
The pregnancy proceeded with Eden staying strong. Hearing her heartbeat at each appointment was a joy. Dennis built her a tiny casket and I knit a little baby blanket to put in it. Not your typical prenatal activities, but we wanted to do special things just for her because we knew our time was so limited.

We scheduled induction on her due date in late January, but I wasn’t mentally or physically ready; I knew it would be the beginning of the end. We rescheduled for February 9 and planned for our extended family to be there.

Eden’s birth went wonderfully. I was able to do a water delivery and there was plenty of staff on hand to help with everything. Eden was tiny, but strong. We baptized her and took dozens of photos, which we cherish to this day. That night we decided we would leave the hospital right away in the morning, so as not to get swept up in unnecessary testing and such.

Eden was held almost every minute of her life. Everyone we knew came to see her and hold her. We fed her breast milk with an eyedropper and eventually she was able to nurse. My sister would stay up all night with her so I could try to sleep. Eden survived much longer than anyone had predicted and we celebrated her one-week birthday with cake and sparkling grape juice in miniature champagne glasses. We still use those glasses every year on her birthday.

Our hospice nurse was an incredible blessing. She was the one who was able to fill the morphine prescription (such tiny doses) when the local pharmacies were unable to do so. She was the one who came to the house when I saw that Eden was starting to have a bleed in the back of her head. She was the one who came to pronounce the time of death after Eden, eleven days old, died in her daddy’s arms.

Looking back on our experience, we feel fortunate that we had an incredible staff that had the experience and knowledge to support us. From diagnosis through Eden’s funeral, they were there both on and off schedule to meet our needs and calm our fears. Some of the things we feel were most important that caregivers can do include:

- Providing the family with correct diagnosis and accurate information so they can plan accordingly;
- Having a primary care coordinator who is knowledgeable about the condition;
- Putting a birth plan in place. Say yes to requests that are allowed in normal pregnancy and delivery (i.e. water birth, family present). Let it be a normal, joyful experience rather than an intervention;
- Encouraging the family to name the baby and expecting the staff to call him/her by name. It validates the life of the child and draws everyone closer to him/her.

We happen to be blessed with a large family as our support system, and some of the most helpful things they did for us included:

- Being there physically. It is a long-term commitment!
- Listening to our concerns over and over;
- Helping with childcare, household duties, farm work, etc. so we could focus on Eden;
- Taking family photos.

If a couple does not have much family support, we feel it would be extremely helpful to connect them with a support group. The one thing I desperately wanted when we were on our journey with Eden was to personally talk to another family who had been through an experience like ours. That did not happen for us, but perhaps with networking it could be available to other families.
Care providers should keep in mind that everything they say and do can have a tremendous impact on the family’s experience. The smallest comment can cause a great deal of consternation for the family. Please take time to listen carefully to the family’s concerns. Your wisdom and experience are crucial, but I encourage you to empower families to be fully involved in the birth and death of their child.

Now that we have walked the “unfamiliar road,” I can tell you that it was an amazing journey. So many people helped us make Eden’s birth and life a tiny little paradise for us. We thank them. Eden’s life was a bittersweet journey, but we wouldn’t have missed it for the world!
Not long ago, it wasn't possible to know before birth that a baby would be born with a life-limiting condition such as anencephaly, Trisomy 18, or Potter's syndrome. With advances in prenatal testing, many conditions now can be detected relatively easily before birth. But then what? Terminating the pregnancy, of course, is one option. In many places, that course of action is recommended and expected. But a significant number of parents wish to continue their pregnancies and embrace whatever time their baby is able to have, within the womb and without.

This relatively new phenomenon is inspiring a new response: perinatal hospice and palliative care, which is an innovative and compassionate model of support that can be offered to parents who learn during pregnancy that their baby has a life-limiting condition. This support is a model of caring for the family from the time of diagnosis—before, during, and after birth. It can easily be incorporated into standard pregnancy and birth care.

Perinatal hospice is not a place. It is more a frame of mind. It can be thought of as "hospice in the womb" (including birth planning 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). Palliative care can also include medical treatments intended to improve the baby's life. This approach supports families through the rest of the pregnancy, through decision-making before and after birth, and through their grief. Perinatal hospice enables families to make meaningful plans for the baby's life, birth, and death, honoring the baby as well as the baby's family. It is a beautiful and practical response to one of the most heartbreaking challenges of prenatal testing.

The concept was coined in 1995 by Drs. Byron Calhoun and Nathan Hoeldtke, who drew upon the concept of adult hospice care, a movement begun by Cicely Saunders in Great Britain in the 1960s to address a lack of care for the dying. “We propose a model of care that incorporates the strengths of prenatal diagnosis, perinatal grief management, and hospice care to address the needs of these families,” Calhoun and Hoeldtke wrote, describing a team effort that would include maternal-fetal medicine subspecialists, obstetricians, labor and delivery nurses, and many others (1).

Caregivers can provide support during pregnancy, including assisting with birth planning, making medical decisions for the baby, offering support for anticipatory grief, and thinking about experiences with the baby both before and after birth. And then caregivers can provide support when the baby arrives, helping parents create memories, including extended families, and supporting families as they say goodbye. It’s also important to note that some babies surprise everyone and are able to live longer than expected. Babies with the same diagnosis can vary greatly in their ability to sustain life. They are individuals, not diagnoses. Caregivers can provide support as events unfold and as new decisions may arise, helping the family follow the baby's lead.

The concept fits well with the general definition of palliative care from the World Health Organization, which describes it as care that improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, along with spiritual and psychosocial support from diagnosis to the end of life and bereavement (2). According to the WHO, palliative care "affirms life
and regards dying as a normal process" and "intends neither to hasten or postpone death," principles that align well with families choosing to continue these pregnancies. How many parents actually do this? One early report, written before the spread of perinatal hospice and palliative care, estimated that about 20 percent of parents chose to continue their pregnancies—even in the absence of support (3). But the percentages increase dramatically when parents are offered perinatal hospice support and reassured that they will not be abandoned by their caregivers. In one British study, when parents were offered perinatal hospice as an option, 40 percent chose to continue (4). In a U.S. study, when parents were given the option of perinatal hospice, the number rose to 75 percent (5). And in another U.S. study, the number who chose perinatal hospice was 85 percent (6). Even if the overall numbers are small, these parents need and deserve best-practices care. The need is likely to continue to grow, especially as testing continues to advance and as awareness spreads. Parents are hearing about perinatal hospice and palliative care through the Internet, through other parents, and through significant coverage in major media, such as a front-page story in The New York Times (7), a lead story on MSNBC.com (8), and many others (9). The topic has also been addressed by numerous articles in medical journals (10) as well as health-related media such as the Canadian Medical Association Journal (11).

Some might question why parents would put themselves through a pregnancy like this when there’s no hope. I—and other parents who have traveled this path—invite skeptics to consider that parents can find different kinds of hope. They may hope the baby is born alive. They may hope that the baby be treated with dignity. They may hope that the baby be remembered. Those are profound kinds of hope. Parents who have chosen perinatal hospice have said that this kind of care helped their hopes be fulfilled. Continuing the pregnancy is not about passively waiting for death; it is about actively embracing the brief, shining moments of this little life. It is a beautiful, rational, healing choice.

Initial concerns often revolve around the mother’s physical and emotional health. Small studies indicate that these pregnancies are often otherwise physically normal for the mother (12), and abortion poses physical risks of its own, especially later in gestation (13). In an era of evidence-based medicine, it’s important to note that there is no research to support the presumption that terminating the pregnancy is easier on the mother psychologically. In fact, research to date suggests the opposite (14). Termination is not a shortcut through grief. Another major concern for most parents is whether the baby will suffer during pregnancy or after birth. Many life-limiting conditions are not inherently uncomfortable for the baby. (See A Gift of Time: Continuing Your Pregnancy When Your Baby’s Life Is Expected to Be Brief for parents’ poignant descriptions of their baby’s peaceful life and death.) If pain is a possibility, it can be treated aggressively and effectively, and pain can be avoided altogether by careful decisions about medical intervention. A terminally-ill baby does not have to be rushed to intensive care or surgery or a ventilator. Parents can even decline minor routine procedures such as standard newborn shots and tests that would cause unnecessary discomfort. The baby can instead be enveloped in comfort and love.

Perinatal hospice and palliative care also reflect newer understandings about caring for parents experiencing perinatal loss. Outdated practices forbade parents from seeing a baby who was dying or stillborn. Into the 1980s and even later, caregivers often advised parents to forget about it and have another one, and babies' bodies often were disposed of as medical waste. A baby's death was treated as a clinical and fleeting medical incident. These practices may have become routine out of compassion, to try to protect parents (and perhaps caregivers) from painful situations. Yet parents and caregivers eventually realized that these practices hurt rather than helped. They failed to honor the baby or the parents. Many hospitals have now adopted more sensitive practices. For example, caregivers now often encourage parents to see their baby, hold their baby, collect handprints and footprints, take photographs, and generally help to acknowledge that this is a real baby and this is a real loss. Babies' bodies are cared for tenderly and buried or cremated with respect; parents' grief is considered a healthy, normal response; and the baby is recognized as a unique, irreplaceable child. Now we have a new population of patients,
created by advances in prenatal testing. This is an opportunity for a new kind of care that incorporates newer understandings and avoids repeating mistakes of the past.

Perinatal palliative care is an appropriate option for patients whose babies are diagnosed prenatally with conditions that are unquestionably lethal. It’s also appropriate for families who are faced with decisions about aggressive medical intervention. That decision is often framed as “saving your baby” vs. “doing nothing.” What parent wants to do nothing? But palliative care is not nothing; it’s a different kind of care. It can include palliative measures that may extend life or make life more comfortable for the baby. Some families are looking for a third way, another option besides termination or massive intervention. Perinatal hospice offers a third way (15).

Fortunately, perinatal hospice and palliative care programs are forming to meet this need. More than 150 pioneering hospitals, hospices, and clinics in the U.S. and around the world are now listed on perinatalhospice.org. As of this writing, support is available in 36 U.S. states as well as in Australia, Canada, England, France, Ireland, Italy, New Zealand, Nicaragua, Norway, Poland, and Spain.

For many of those involved with ChiPPS, the concept of perinatal hospice and palliative care is not new because they are already offering this important care to their patients. On behalf of parents, I extend my gratitude to these pioneers. For those who haven’t yet ventured into these waters, it is likely that patients will come your way hoping—or expecting—to be supported well through a pregnancy like this. Many resources for starting a program are available (16), including a Perinatal Palliative Care Toolkit and position paper on perinatal palliative care (17) from RTS Bereavement Services at Gundersen Lutheran Medical Foundation (18) and a framework for perinatal palliative care from the British Association of Perinatal Medicine (19).

Dr. Calhoun describes parents’ reaction this way: “Parental responses have been overwhelmingly positive. These parents are allowed the bittersweetness of their child's birth and too-soon departure. Grief lessens as time passes and parents rest secure in the knowledge that they shared in their baby's life and treated the child with the same dignity as a terminally ill adult” (20).

And in the words of one of more than 100 parents who shared their experiences for A Gift of Time:

"By giving my son the protection of my body to face the announced death, I was giving him life, all of his life, so that it would be recorded in our family, in all of our history, and in the hearts of each of us. It wasn't a morbid walk but a formidable surge of love." — Isabelle (21)

Amy Kuebelbeck edits perinatalhospice.org, a clearinghouse of information about perinatal hospice and palliative care. She wrote Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life (Loyola Press, 2003), a memoir about her own experience, and 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), co-authored with Deborah L. Davis, Ph.D.

References
2. World Health Organization: Palliative care. who.int/cancer/palliative/en/
9. See list of media coverage at perinatalhospice.org/Media_coverage.html.
10. See bibliography at perinatalhospice.org/Resources_for_caregivers.html.
12. For discussion of maternal physical health, see:
14. For discussion of maternal emotional health, see:
15. For one family's story that includes decisions about medical intervention, see Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life by Amy Kuebelbeck (Loyola Press, 2003).
16. See perinatalhospice.org/Resources_for_caregivers.html
I remember the day when a young bereaved mother called to talk to me about the death of her baby at 17 weeks gestation. She was overcome by the intensity of her feelings and wanted to voice a concern about her care. At the time of her baby’s death, she and her husband had decided not to see, hold, or name their baby, nor did they want to know the gender. They both thought that knowing the sex of the baby would add additional grief to their already broken hearts. She was upset by the bereavement counselor's follow-up phone call. In the conversation, the counselor told her, "We have the pictures of your son. Would you like us to keep them or would you be more comfortable coming in to see them?" The mother was so shocked by this. Her rights had been violated! Her choice had not been respected.

Recently, I had another mother call me whose baby died fifty years ago. She shared with me her haunting experience. Her stillborn baby girl was whisked away without her seeing her, not named and buried without family with six other babies. She was not given any choices and told me it took her 35 years to finally have the courage to name her baby in an official ceremony with her closest circle, but she is still hurting due to this horrific experience. She is so happy knowing that bereaved families of today have so many choices and opportunities to memorialize their precious babies; it comforts her to know they will have healing experiences.

I also have had a caregiver say to me, "I did not choose to see my baby who died at 16 weeks. I still do not understand why we give families all these options." This caregiver made her choice, but that does not mean it is the right choice for her patients. She has the responsibility to give her patients information and options, even if she disagrees with their decisions. The choices families make may not be our choices, and this can be disturbing and make us feel frustrated or guilty. Acknowledge your own feelings because they are very real, however, rest assured that if you have presented the options to the best of your ability and with compassion, the choices made will be the right ones for the bereaved families you serve at that moment.

In the twenty-nine years I have ministered to families who have experienced the death of their baby, I continue to be touched by the individuality of each death. Each footprint that is left on the hearts of the parents is unique and different from every other footprint. Therefore, the parents’ reactions and choices will be different and varied. Caregivers can get into trouble when they assume each family will or will not want to see, hold, touch, name and bury their baby. Caregivers need to be careful not to force, but rather gently explain patients’ options. Some caregivers even feel they have failed if the bereaved parents did not choose the options they felt would aid in their healing. There is no right or wrong choice. However, choices are influenced by the degree of information as well as the amount of time bereaved parents are given to make these important decisions. Remember, the most vital part of decision-making is affected by the way caregivers present options.

As caregivers, we can play a critical role in the healing process by laying the foundation for a positive grieving process. Realize how special you are and how much your patients and their families look to you
for compassion and guidance. Know it is an honor to share this devastating time with parents and their beloved baby. They will never forget your caring presence.

Rights of Parents

The term "rights" is not used as a mandate for the bereaved, or as a militant statement of demands. It is an affirmation for parents who wish to be involved with their baby, to make decisions based on informed consent, and to assume the parenting role in meaningful ways despite the tragic circumstances. As Sister Jane Marie Lamb, OSF so poignantly stated in her article “Parent’s needs and rights when a baby dies,” “Every minute is significant, every decision important for the future peace and healing of these parents.” Many, however, are afraid to request anything our society might consider morbid, unusual, or weird. This document serves as a guideline for the possibilities and options available to parents and gives them "permission" to follow their parenting instincts within the limits of state, local, and hospital policies.

Before you have a conversation with the parents, acquire as much information about the patient and her significant other as possible. Review her chart and prenatal record and then talk to her primary caregivers. Also, ask the patient’s caregiver if she and her support system have voiced any concerns. This better prepares one to obtain answers for these worries or fears when you enter the room.

It is important to use a checklist to enhance continuity of care plus an organized packet. Every staff person who cares for the patient and her family needs to document on this checklist, and it should be a permanent part of the patient’s medical record. To stay organized, develop a bereavement packet that includes grief pamphlets or booklets and resources for the patient as well as the necessary forms and paperwork caregivers need to complete.

Before you walk into the room to begin presenting the options, try to have a quiet moment to yourself. This may help you to be focused and allow you to be present to each family and their needs. Introduce yourself and explain your role of caregiver to each of them. Express your sympathy by saying, "My heart goes out to you at this time. I am here to support you through this challenging time.” You may touch their hand or arm. However, sometimes you may sense they are not comfortable with touching, so refrain from doing so in that instance. Encourage all persons in the room to sit down and pull up a chair close to the patient and ask if they would like to share their story with you; I have even simply stated, “Share with me what your baby has meant to you and your family.” As the parents share their story, you may discover some very important details that help you to understand what the loss may mean to this mom/couple and their support system.

Before proceeding, ask the mom and her partner and/or support persons if they have any immediate questions or concerns. Sometimes this allows for a natural lead into the options; other times there are no questions, so begin talking about choices as gently as possible.

The Rights of Parents, Rights of Parents Whose Baby Dies Very Early in Pregnancy, Rights of Children When a Sibling Dies and Rights of the Baby are not meant to be hard and fast rules. Rather, they are meant to guide caregivers in ensuring that all parents grieving the death of a beloved baby are allowed to care for and make memories with their baby in ways that are best for their family. The following narratives describing each of the Rights of Parents and Baby give suggested ways to implement these rights when working with bereaved families.

1. To be given the opportunity to see, hold, touch, and bathe their baby at any time before and/or after death within reason. Instead of directly asking if they would like to see and hold their baby, ask, “Can you share with me your feelings about seeing the baby?” Many times, fears about the appearance of the baby will arise. Address those fears as honestly as possible, and assure them that you will prepare them for possibilities, i.e., skin tears, skin discoloration. Tell them that, as with all babies, they will see special family features of each of them. Let them know they can hold the baby or put the baby in a special basket and spend as much time with their baby as they need. Inform the parents that their decision may
change as time evolves, and they may feel different after the baby is born. They may choose to not see or spend time with their baby and that needs to be respected.

2. To have photographs of their baby taken. As caregivers, we know the time at the hospital or funeral home is the only opportunity to take pictures of the baby. If photography is not culturally accepted, still ask to be clear that this is not an option. For other families, ask, “How does it feel if we take pictures of the baby?” For some this may feel morbid and others are unsure. It is important to state you have a facility policy of taking some photographs. No one should be forced to take or to view the pictures, but they should be kept in a safe place for the parent should they ever want to see or have them. Explain the process of taking these special pictures, which include positioning the baby, special props, and clothing. It is important to take digital photos or 35mm pictures, and professional pictures. Most facilities have professional photography companies that provide well baby and also bereavement pictures. In addition, local communities may have trained volunteer bereavement photographers that provide beautiful pictures free of charge. Some families choose to take an active role and use their own camera and/or video recorder. Some wish to have family pictures taken. It is not uncommon, though, for parents to be uncomfortable and refuse to have any additional pictures taken; this should be accepted and not forced on the parents.

3. To be given as many mementos as possible. Explain that past bereaved families have expressed the need for mementos of their babies. Share with them the keepsakes you will provide, i.e. baby book, memory box, crib card, baby name bracelets, photos, lock of hair, permanent foot and hand prints, and records of weight and length. Parents find great comfort picking out an outfit that the hospital provides or using one they have brought from home. Any item the baby’s skin touched means a great deal to the parent – such as a blanket or a prop from the picture. These items are all tangible evidence that the baby existed, and it has been found that these items aid in the parents’ healing. Sometimes, the mementos may be overwhelming, and the family may decide they do not want them. If this is their choice, the mementos need to be kept in a secure place. Many times, the family decides at a later date that they want their baby’s keepsakes.

4. To name their child and bond with him or her. Instead of directly saying, “Are you going to name this baby?” Gently ask, “Can you share with me the names you picked out during the pregnancy?” Ask the meaning of the names and how that decision came to be. This allows a very special conversation about this process and their connection to the baby. Then explore if they would like to use one of their chosen names. Sometimes, parents are very comfortable using the name they had originally chosen, and in other instances, they may need to explore another name. If they had not picked out a name, ask if they feel comfortable naming the baby. Frequently, you may hear an immediate “Yes” that the baby will be named. Other times, they may say no or exhibit some uncertainty about this option. Advise them that there is no pressure to name the baby—no one should be forced to make this decision quickly. Occasionally, families may want to look at the baby or feel they need to ponder this option. Some may feel the need to peruse the many popular baby name books. There are some parents who leave the hospital without naming their baby and name their baby months and even years later. However, as soon as a name is chosen, begin to honor the baby by using his/her name in your conversations. Another way to honor the baby is to provide a naming ceremony, blessing, or baptism if the family desires.

5. To observe cultural and religious practices. When I was a new OB nurse, I was always concerned that I was not completely aware of each culture and religion and their beliefs. As years passed, I attempted to educate myself by reading and attending workshops. I gleaned valuable insights through this process. I am now more aware of different beliefs, but I have found that even individuals in the same faith or culture may have very different ideas. Therefore, when ministering to parents, invite them to share their individual beliefs, past traditions, and rituals regarding each choice with you. In the case of mixed faith relationships, an attempt should be made to find a middle ground. Typically, their minister, rabbi, or priest
may perform rituals; however, they may not have a religious background or an established religious community. The hospital chaplain can provide support and rituals as well.

6. **To be cared for by an empathetic staff.** Many of the parents who contact me share that their healing was made easier through the sensitive, caring individuals who assisted them during their darkest hours. It is imperative to continue to provide on-going education regarding perinatal loss to hospital staffs via conferences, workshops or bereavement DVDs. Recent cuts in funding for education and time constraints have made this opportunity challenging. Many perinatal organizations now provide online courses and professional support.

7. **To be with each other.** With today's family-centered OB units, hopefully, it is a given that one's support system will be allowed to stay with the mother twenty four hours a day, plus be near during all procedures. This policy should include the father or partner of the mother and in the case of a single mom, her support person as well.

8. **To be given time alone with the baby.** After parents have had some time with the baby in your presence, explore if they would like time alone with their baby. Provide them with a bassinet or basket for the baby, items for bathing the baby, extra baby clothing, a rocking chair, CD player with soothing music, and a camera. Assure them that this is their time and no one will intrude. Always remind the parents you are available and that they can call you for support during this time if they choose. If the baby needs to be taken to the morgue, additional request(s) may be made later to see the baby again. These requests need to be honored. The baby should be brought back up to the nursing division, warmed on the baby warmer or placed in a warm blanket so parents can have additional time with their baby.

9. **To be informed of the grieving process.** Many times, parents are unable to process all the information given to them initially due to their feelings of shock. This may be the first time they have experienced a tragedy, and they may be overwhelmed by the intensity of the many feelings of grief. It may be challenging for them to read a large publication, so small vignettes or brochures that explain the grief process are easier for them to read and digest and should be included in their take-home packet. In addition, the mourning needs of siblings, grandparents, and other family members should also be addressed and acknowledged with appropriate resources made available for these needs.

10. **To be given the option of donating their baby's cartilage, tissue and/or organs for transplant or donating the baby's body to science.** In general, attention has been brought to the forefront about tissue and organ donation. This opportunity can only occur if a baby is of designated gestation and/or a live birth. Laws have been passed to explore these donor options after death. Facilities have trained organ donor representatives who have printed materials and the knowledge to explore these options. If the family has an interest in donating the baby's body to science, some research would need to be done at a local medical university to see if this is a possibility.

11. **To request an autopsy or pathology exam and genetic testing.** It is not uncommon for parents to be frightened by the prospect of any testing, and they may be unclear of the need or reason for an autopsy or pathology exam. It is vital that their physician(s) discuss these options and the possible reasoning and/or benefits for these procedures. Other concerns may be the cost involved or their lack of information regarding the procedures. Their fears and concerns of each option are points of discussion. Some do not want their baby to be subjected to any additional procedures while others feel it is important to search all possible avenues for answers. If possible, delay the autopsy until the family has spent the desired time with the baby. However, the baby can still be seen by the family after the autopsy at the hospital. Families need to be informed that the final results of an autopsy or genetic testing make take 6-8 weeks for the report.
12. To have information presented in understandable terminology. Everyone has the right to comprehend the material presented to him or her. It is imperative to speak in terms that parents will understand. Also, due to their state of mind, they may need to have the information repeated more than once. It is crucial to have an interpreter for non-English speaking persons or someone to sign for a deaf person.

13. To plan a farewell ritual, burial, or cremation. Instead of asking the family, "Are you going to have a funeral?" Simply state, "Share with me the traditions of your family regarding funerals and rituals." With this question, you often find out their past experiences, faith background, or spiritual needs in regards to death. Acknowledge how difficult planning a funeral might be for them since this could be the first time young parents may be attending the funeral of someone in their immediate family, let alone planning one. Share with them your willingness to help them in addition to their clergy (if there is someone) or funeral director. If they do not have a religious affiliation, you may be their main resource. Encourage them to personalize the ceremony as much as they want to. Address their cultural and religious traditions in regards to the rituals. Also, provide them with printed information regarding area funeral homes/cemeteries along with options and costs. I have assisted many families through this challenging process, and I am always amazed at the individuality of each farewell ritual. It is vital to be aware of state and local regulations regarding burial, and if the parents' wishes are within regulations, they should be honored.

14. To receive information on support resources. A list of support resources should be given at the time of discharge. A follow-up phone call may need to be made before the farewell ritual to assist them with final decision making. Additional calls or emails should be made to check on the family at established intervals and at difficult times, such as due dates and anniversaries. If a support group is run by the institution, follow-up letters explaining the meeting and upcoming meeting dates and memorial services should be sent by the facilitator. In addition, the availability of other resources such as interactive perinatal loss websites, library books, and videos or newsletters should be noted.

Rights of the Baby

1. To be recognized. It is important to explore what this pregnancy meant to the family. The bonding process may begin very soon in the pregnancy; therefore, hopes and dreams for this baby may have already been established. If the family considers this pregnancy as a human being, this needs to be validated. Avoid insensitive terminology such as the “missed abortion,” “fetal tissue,” or “products of conception or fetal demise.” Acknowledge the baby’s presence by a birth or recognition-of-life certificate. Always use the baby’s name when referring to the baby.

2. To be named. Explore the patient's and her partner's feelings regarding naming the baby. This may be too overwhelming and they may choose not to name the baby. This needs to be respected. If they are indecisive, let them know there are no time limits. Others have named their baby weeks, months, and even years later.

3. To be seen, touched, and held. In respect to the baby, he/she should be presented as a live baby would be presented—in a soft blanket and beautiful clothes. When families see their caregiver respect and cuddle the baby, they may find it easier to do so themselves. If the parents choose to not see, hold, or touch the baby, this should be abided by. However, they may be grateful if you held their baby even if they could not.

4. To have life ending acknowledged. A farewell ritual may be very helpful in acknowledging the short time this baby was here. Give parents information on the different styles of birth and death announcements available. Explain the many creative ways of memorializing their baby, from memory
books and boxes, to tree plantings. Holiday memorial services and remembrance walks honor these precious babies in the years to come.

5. **To be put to rest with dignity.** Burial or cremation options should be explained to all families regardless of gestation of pregnancy. All states have strict regulations for proper care of baby’s remains over twenty weeks gestation in which a baby must be buried or cremated. There are no state regulations for babies that are delivered or miscarried prior to twenty weeks gestation; thus the remains in some medical institutions are considered medical waste. However, many facilities have established policies and have collaborated with funeral homes and cemeteries to respectfully care for the remains of babies under twenty weeks gestation. Some even have a quarterly group burial and remembrance service families can attend. Some states have laws that mandate that the patient experiencing early loss be informed of the hospital disposition policy and also are given the right of private disposition. If there is a hospital disposition option, a minimum thirty day waiting period for burial/cremation allows families to reconsider their decisions. Invitations should be extended to families to attend the group burial or memorial service. Parents have the right to know where their baby is buried, and a memorial headstone at the group burial site is comforting. Burial cradles for tiny babies less than twenty weeks are available for a dignified burial. Nurses and other caregivers who support families experiencing the death of a baby play a pivotal role in ensuring the baby and other family members are treated respectfully. By implementing the Rights of Parents into the care provided at the time of the loss and in the following months, you will validate the important role each baby has in his or her family as well as assist parents in creating memories they will treasure for a lifetime.

**References**


The Rights of Parents and Babies were originally revised and enhanced by Sr. Jane Marie Lamb, OSF and Foundress of Share, from a document developed by the Perinatal Bereavement Team at Women’s College in Toronto, Canada. The Rights were updated in 2008 by the National Share Office Staff. The Rights of the Parents and the Baby can be used as guidelines for institutions and as a handout for parents.
Rights of Parents When a Baby Dies

1. To be given the opportunity to see, hold, touch, and bathe their baby at any time before and/or after death within reason.

2. To have photographs of their baby taken and made available to the parents or held in a secure place until the parents wish to see them.

3. To be given as many mementos as possible, e.g., crib card, baby beads, ultrasound and/or other photos, lock of hair, baby clothing and blankets, feet and hand prints and/or permanent molds and record of weight and length.

4. To name their child and bond with him or her.

5. To observe cultural and religious practices.

6. To be cared for by an empathetic staff who will respect their feelings, thoughts, beliefs and individual requests.

7. To be with each other throughout hospitalization as much as possible.

8. To be given time alone with their baby, allowing for individual needs.

9. To be informed of the grieving process.

10. To be given the option of donating their baby’s cartilage, tissue and/or organs for transplant or donating the baby’s body to science.

11. To request an autopsy. In the case of miscarriage, to request to have or not have an autopsy or pathology exam as determined by applicable law.

12. To have information presented in terminology understandable to the parents regarding their baby’s status and cause of death, including autopsy and pathology reports and medical records.

13. To plan a farewell ritual, burial or cremation in compliance with local and state regulations and according to their personal beliefs, religious or cultural tradition.

14. To be provided with information on support resources which assist in the healing process, e.g., local support groups, perinatal loss internet support, counseling, reading material and perinatal loss newsletters.

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Rights of Parents Whose Baby Dies Very Early in Pregnancy

Parents who have experienced an early pregnancy loss should have the opportunity:

1. To be with each other during any tests, procedures or hospitalization as much as possible.

2. To be cared for by an empathic staff who will respect their feelings, beliefs and individual requests.

3. To have information presented in terminology understandable to parents regarding their baby’s status and or cause of death (if known), including pathology reports and medical records.

4. To be told all options and to be given the choice (when medically possible) on how to proceed when their baby has died, such as D&C, natural delivery or delivery induced by medications.

5. To be able to see and hold their baby and take photographs if possible.

6. To be given the option to name their baby if they choose to, whether or not the gender is known.

7. To observe cultural and religious practices the parents feel are appropriate to the situation.

8. To be informed of the grieving process and to be given referrals and resources that will help them through their grief.

9. To be offered as many mementos as possible, for example, ultrasound photos, memory box, certificate of life.

10. To be given information on the facility’s disposition policy and offered choices whenever possible.

11. To be given options regarding farewell rituals such as a hospital memorial service, a balloon release, or a private burial at home.

12. To receive follow-up appointments for medical tests and genetic counseling or to review lab test results.

13. These rights should be granted to parents no matter how early in the pregnancy their loss occurred.

Adapted from “Rights of Parents who Experience an Early Pregnancy Loss” by Perry-Lynn Moffit, co-author of A Silent Sorrow and endorsed by Share Pregnancy and Infant Loss Support, Inc. and pregnancy and perinatal loss support groups and leaders nationally. Reprinted here by permission.
Rights of the Baby

1. To be recognized as a person who was born and died.

2. To be named.

3. To be seen, touched and held by the family.

4. To have the end of life acknowledged.

5. To be put to rest with dignity.

Rights of Children When a Sibling Dies

1. To be acknowledged as individuals who have feelings that need to be expressed.

2. To be given the choice to see and hold our sibling before and after the death within reason.

3. To be considered in the choices parents are given, we may have opinions on such things as plans for funeral, baby's name, etc.

4. To be informed about the feelings of grief in our terms, giving us the choice of a support group or counselor.

5. To be recognized by our society that we will always love and miss our sibling.

Adapted from "Rights of Parents who Experience an Early Pregnancy Loss" by Perry-Lynn Moffit, co-author of A Silent Sorrow and endorsed by Share Pregnancy and Infant Loss Support, Inc. and pregnancy and perinatal loss support groups and leaders nationally. Reprinted here by permission.
THE BENEFITS OF A PERINATAL PALLIATIVE CARE PROGRAM

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When parents receive a life-threatening diagnosis for their unborn baby, time stops. They are shocked, dreams are shattered, and decisions need to be made. Parents are likely thinking, “What happens now?”

Having a perinatal palliative care program (PPC) in place allows health professionals to guide families through their decision-making process and offers them options of care. Perinatal palliative care can begin when the diagnosis is made prenatally, before delivery, after discovery at birth, or in the NICU. Palliative care emphasizes comfort measures but does not necessitate stopping life-sustaining therapies. Unlike hospice, palliative care has no time restriction for care—the baby can live for minutes, days, months, even years and receive palliative care (Limbo, Toce, & Peck, 2008, 2009).

Since Resolve Through Sharing® began in 198, Gundersen Health System has promoted family-centered bereavement care for anyone needing palliative services. In 2008, a multidisciplinary task force created the Blueprint for a Perinatal Palliative Care Program® to address the needs of families whose babies are diagnosed with a life-threatening condition. The program provides structure and education for staff who guide families through these difficult decisions, as well as written and referral resources for families. Key components include a standard operating procedure (SOP), algorithms, and access to professionals who can best help the family. These professionals serve as primary care providers, referral sources, and liaisons, and form a network of hospital, ambulatory, and community-based services for the parents, their baby, and family. Advance care planning, including birth planning, is included in all PPC.

Experts in a seamless systems approach to providing health care recognize the need for clearly defined processes that support compassionate, individualized care. The SOP helps guide the health provider in delivering the appropriate care for the family and baby who has a life-threatening diagnosis. Algorithms that address what to do when a referred patient with a possible fetal abnormality presents, when an unexpected fetal abnormality is identified, and other scenarios have been created to provide a consistent approach to diagnosing, delivering difficult news compassionately, and informing families of options. The SOP and algorithms support relationship-based care. The maternal-fetal medicine physician offers further evaluations and, if possible, treatment, and available resources are discussed and offered. With the family’s consent, appointments are made with specialty departments as indicated by the diagnosis. These appointments happen quickly, usually within two business days. Meanwhile, the family has telephone numbers for a key contact person, the labor and delivery unit, and the telephone nurse advisor should questions arise while they are waiting, which helps the family feel supported.

Numerous professionals are involved with families who choose PPC. Two featured here are the genetic counselor and neonatologist. According to Kevin Josephson, certified genetic counselor, meeting with a genetic counselor benefits the family by helping parents understand the diagnosis, severity, prognosis, and available options for treatment and continuation of the pregnancy. Understanding allows the parents to make the best decision possible for them as they parent their baby with a life-threatening diagnosis. According to Dr. Suzanne Toce, retired neonatologist from Gundersen Health System, antenatal neonatal consultations are valuable for a number of reasons. Parents learn information about the baby’s concerning problems, such as chances of survival, types of medical issues that need immediate attention in the newborn period, possible course, signs of imminent dying, and potential lifespan. The consultation also helps parents understand their role in decision making and the options for caring for their baby. The neonatologist, too, benefits from this consultation appointment by meeting with and learning from the
parents what their coping skills include, what resources they have available, their previous experiences, and any goals they have that will affect their decision making (Toolkit for a Perinatal Palliative Care Program, 2008, 2013).

When a family decides to continue the pregnancy, they help create a birth plan of care and a neonatal advance care plan. The birth plan of care includes decisions such as having music, photographs, skin-to-skin care, or a desire to have a water birth. The neonatal advance care plan is not intended to be directive but to include goals of care. It may not address all issues but can be adapted to meet the needs of the baby and family as the course of care continues. Issues that can be addressed in this section include resuscitation status and medical treatments that are consistent with the goals of care, including oxygen, comfort measures, or any laboratory testing. This portion of the plan would also include preparations for rituals; home going, if that is an option; care for the body if death occurs in the hospital; or other anticipated needs of the baby or family. These plans become a part of the electronic medical record and can be accessed at any time of day or at any point of entry into the hospital.

Offering PPC allows parents to parent their baby by making choices and identifying goals of care immediately at diagnosis. It gives parents the chance to create memories, to love their child, and to parent according to the goals they have identified for as long as possible. Ideas for incorporating a PPC program into an existing perinatal bereavement program and suggestions for staff education can be found in the literature (Kauffmann, Hauck, & Mandel, 2010; Kobler & Limbo, 2011).

Bereavement Services of Gundersen Health System, La Crosse, Wisconsin, can help a facility create a PPC program through continuing education offerings, archived webinars, written materials, and consultation. For example, the workshop Blueprint for a Perinatal Palliative Care Program®, held first in 2009, is offered every August in La Crosse, Wisconsin. This workshop provides current, evidence-based information for health providers who care for families with babies with life-threatening conditions. The theme of the conference changes annually. At the request of past participants, in 2013 we will provide an additional workshop for health providers who do not have a program established in their facility and desire basic information to establish a program. This workshop will be held the evening before the day-long Blueprint conference. Participants will hear from those who were involved in creating a PPC program and utilize the Toolkit as a framework to begin the process of creating their facility’s own program. To find out more about these programs, the Toolkit, and consultation, visit www.bereavementservices.org or call 608-775-4747.

References


COMMUNITY PEDSCARE PERINATAL PROGRAM

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Community PedsCare (CPC) is the pediatric hospice and palliative care program of Community Hospice of Northeast Florida providing supportive services to children from birth to age 21 with life-limiting, life-threatening, complex chronic conditions, and their families in the five counties in the northeast Florida area. In 2006 CPC began offering perinatal support through its Perinatal Program (PNP) to families who were told that their unborn child had been diagnosed with a life-limiting condition, may not survive birth or life outside the womb. To ensure understanding of the supportive services available to be provided through the Community PedsCare Perinatal Program, appropriate forms and consents were developed and approved in collaboration with the organization’s Compliance Department. These forms include Rights and Responsibilities, Notice of Privacy Practices (HIPPA), and the Family Birthing Plan (which is attached to this article). Additionally, through use of the organization’s electronic medical record system (EMR), information on referrals, demographics, and admissions to the perinatal program is captured and available for service provision purposes as well as data collection and tracking perinatal needs of the community.

When the family chooses to accept the supportive services offered through the Perinatal Program, the mother signs the consent ensuring awareness of the scope of services offered and that her obstetrician will remain her physician for the delivery of the baby. The services offered to families include development of a birthing plan, psychosocial, spiritual, and child life support for the mother and family throughout the pregnancy, and grief and bereavement support in the case of death. Families may choose all disciplines to be involved or may only want assistance with the development of the birthing plan. Infants who survive after their birth are admitted into one of CPC’s hospice or palliative programs. Through admission into a CPC program, the families experience a seamless transition from hospital to the home setting. Specific to the mother and infant’s physical conditions and following the goals of the mother/family, some families choose to remain in the hospital for the added support while other families are eager to get home as soon as possible.

At this time the perinatal program is unfunded; there is no billing for any perinatal services provided by the CPC team. All funding is provided from philanthropic resources and the PNP program is a highly regarded service promoted by the organization and the community.

Referrals to CPC perinatal program largely come from the efforts of the area’s Fetal Diagnosis Group and Therapy Center. This group was formed through the alliance of pediatric neurosurgeon, Dr. Hector James, and others who recognized the need to address fetal diagnoses that may be incompatible with life. Comprised of providers from Genetics, Cardiology, Neurosurgery, fetal echo program, high risk obstetrics, and the pediatric hospice and palliative care physician, this groups meets monthly to review known cases of perinatal diagnoses and make subsequent recommendations to the Community PedsCare physician who will be working with the mother and family. The sharing of the Birthing Plan initiates additional collaboration with community obstetricians, hospital staff, and other providers who are caring for mother and family.

 Mothers who reside outside of the CPC service area but whose deliveries will occur at a northeast Florida regional hospital are still able to meet with the CPC team for information and service provision. The CPC team will assist them with the Birthing Plan for delivery options, guidance in locating hospice and
palliative care organizations, and bereavement follow up care in the family’s community, as well as collaboration and education to healthcare providers who are going to be providing care through the pregnancy and delivery. Neonatologists covering surrounding areas have developed a close working relationship with the CPC physician.

Initial contact with the family is at the family’s convenience and may occur in their home or at their healthcare provider’s office. CPC staff reinforces to the family their objective of educating on and advocating for the mother/family’s preferences. The mother/family are educated on their options related to the mother’s labor process and subsequent delivery of the baby as well as care for the infant whether still or live born, at the time of delivery and through the course of the infant’s life even if death should occur immediately.

CPC staff help the mother and family speak with others on what is going on with pregnancy. Sometimes difficult discussions arise with family and friends who may have questions regarding the condition or diagnosis of the unborn baby. CPC staff help identify what is available for delivery, monitoring during delivery, and determining what decisions would be made as things progress (possible outcome scenarios). At the time of delivery CPC staff assure that all available support is called in as appropriate and requested by the mother. For example community support organizations such as Now I Lay Me Down to Sleep (photographs), or the hospital social worker and chaplain services and support may be offered/provided. Some families lean on the CPC staff during the entire process; others may prefer an overview of the Perinatal Program offerings and only request minimal intervention or instruction for themselves or their healthcare provider throughout the remainder of their pregnancy and at the time of birth.

Through the Community PedsCare Perinatal Program the following staff members are available: Community PedsCare physician, nurse, psychosocial specialist, chaplain, and child life specialist. However, most families utilize only the physician and nurse. All staff are experts in pediatric palliative and hospice care. Primary staff involved with families receives Resolve through Sharing Training (see the article on "The Benefits of a Perinatal Palliative Care Program" in this issue) and ELNEC-PPC (End of Life Nursing Education Consortium Pediatric Palliative Care) training. Staff providing perinatal support should be comfortable with the delivery of bad news. And, there are times when families need clarification of fetal diagnoses and outcomes or have questions related to the diagnosis and prognosis that the Community PedsCare Perinatal Program staff will address.

The CPC physician and hospital nurse liaison are the first to contact the mother and family, explaining the services available and encouraging, at a minimum, that the family put a Birthing Plan in place. The family will be educated on possible outcomes and with assessment done to ensure the family is prepared as best as possible. Continued collaboration with the family and the other providers as determined by the family’s preferences is provided by the CPC team. The CPC physician and nurse have, at times, been requested by the family to attend the birth; this has been a comfort to many families, particularly first-time moms. Spiritual support is offered by the CPC chaplain, working alone or closely with the family’s personal spiritual leader or hospital chaplain. The CPC chaplain is available and will offer families assistance with funeral or other ritual and ceremonies, as per the family’s request.

The Child Life Specialist (CLS) is frequently requested by families. The CLS prepares the siblings for the delivery/loss through the use of bibliotherapy, medical play, and/or memory making projects. The CLS contacts the mother to discuss memory making options. When the baby is born, the CLS may be requested to go to the hospital to assist with memory making and providing support to the family. The CLS often explains medical concepts, outcomes, and death in age-appropriate language, and occasionally works with extended family who often are caring for siblings during this time. If the baby were to be discharged to home under hospice or palliative care, the CLS many times continues working with siblings in the home.
Bereavement care is offered to all families through the Community Hospice’s bereavement department. Closure visits to the family by CPC staff directly involved may occur for a brief period. The northeast Florida community also has several programs and support groups for those suffering from perinatal loss. The local children’s hospital offers a perinatal loss support group led by one of their chaplains and a hospital social worker meeting twice a month. There is a holiday gathering each December and an annual Walk to Remember in October. Starting in February 2013, there will be a retreat offered to families who have experienced perinatal and neonatal loss. Annually, Community PedsCare holds a day of remembrance service for families who have lost a child in their program. And, Community Hospice’s Camp Healing Powers offers support to children who have experienced a loss (see http://communityhospice.com/Our-Services/Grief-and-Loss-Support/Children-And-Grief.aspx).

There are times in which the CPC staff is faced with limitations about the perinatal support that is available but not requested by the families as some families choose not to address possible birth outcomes or look at decisions of care until after the birth. It is not uncommon that families decide not to talk about the possibility of fetal demise. Ethical issues often arise and deliberation of options is not always welcomed by families or healthcare providers. As with other areas of healthcare, certain diagnoses tend to cause reluctance on the part of possible referral sources/groups. Also if there is lack of agreement among consulting providers, it is critical for the family to hear agreement between the specialists involved. The CPC team works at procuring more of an interdisciplinary meeting among other involved healthcare providers and specialists with a focus on education and mother/family goals.

The offering of this unfunded program provides an invaluable service to the mothers and families affected by untoward fetal diagnoses and the community as a whole. It has also expanded the scope of Community PedsCare’s pediatric hospice and palliative care program. Dependent upon the financial support of Community Hospice and the northeast Florida community, this program affords the ability to provide critical comfort, support, and education to families facing a perinatal diagnosis of "not compatible with life" and to their care providers.

“When other mothers were preparing for childbirth with baby showers or by shopping for baby furniture, my husband and I were choosing a casket and headstone,” says one mother.

“We were able to spend six precious weeks with our daughter due in large part to Community PedsCare,” says Elizabeth’s mom, Sandy. “When she died, it was very peaceful and she was surrounded by her family – at home.” (Please see Sandy’s story, “A Cold Wave Made Warm.” which appears in this issue of this e-newsletter)
Our beloved baby has been diagnosed with

Your compassion and understanding during this bittersweet and difficult time are appreciated deeply. We believe that the memories of our actions during this time with our baby will later console us.

We understand that birth situations may arise that were not anticipated and decisions will need to be made.

We simply ask you to keep us informed so we can participate in the decisions as to what is best for our baby.

We ask that no intervention be taken without our approval, other than what is outlined below. We trust you will respect our wishes.

Please call our baby __________________________. Ask us how we feel and what special stories we have from this pregnancy. This validates and honors our baby’s life.

Please check appropriate box for your request.

☐ We would like to remain in the same room for labor, delivery and recovery. If a C-section is necessary, we want our baby to remain in the operating room with both parents and we want to have recovery in a birthing room to allow for more time together as a family.

During labor and delivery we would like: ____________________________________________________________ (Special music, soothing practices, etc.)

☐ We want to hear our baby’s heartbeat before labor progresses.

We would like ☐ no ☐ external ☐ internal fetal monitoring.

If our baby’s heart stops prior to delivery we ☐ do ☐ do not want _______ to be informed.

We ☐ want ☐ do not want _______ to videotape the birth.

We ☐ want ☐ do not want _______ to have photos during the birth.
We would like to have these people in attendance:____________________________________________
____________________________________________________________________________________

Any medications given during labor to the mother should be given in doses to provide maximum comfort while allowing mother to remain alert.

Please allow ______________________ to cut the umbilical cord.

We would like oral/nasal suctioning for ______________________ ’s comfort only and NO intubation without our permission.

After our baby is born, we ask that he/she be wiped, suctioned, wrapped in a blanket and:
   If alive, handed to: ____________________________.
   If stillborn, handed to: ____________________________.

☐ We wish to cuddle our baby immediately and ask that vital signs, weight, labs and medications be postponed if possible.

☐ If our baby has fewer or more problems than expected, please discuss all options with us.

Other than routine post-delivery care, we wish for private time with our baby. We will discuss exceptions that should be made.

If our baby can’t suck or nurse, we wish to provide comfort with ☐ breast milk or ☐ formula given by ☐ a dropper, or with ☐ placement of a nasogastric/orogastric tube.

☐ We wish to use the services of the hospital chaplain (either for pastoral support or to contact a representative from our faith).

☐ We have planned for our spiritual family to be here for support.

They are: ________________________________________________________________

We are planning a ☐ baptism/christening or ________________________________.

Memorial/funeral plans • have been • have not been made for our baby.
Funeral Home is: ________________________________.

☐ We wish to hold our baby as he/she is dying or has died and want to keep their precious body with us as long as possible.

☐ We would like to bathe and dress our baby. ☐ We have our own clothes.
☐ We need a burial garment.

We have arranged for photos by Now I Lay Me Down to Sleep.
Our photographer is: ____________________________________________________________.
We would like to have keepsake/memory making to include: cord clamp, lock of hair, ID bracelet, crib card, hand and footprints/molds, or ________________________________.

Other considerations:

Signed by:

______________________________    ________________________________
Parent                                      Parent

Date: ________________________________

Our obstetrician: ________________________________

Our Community PedsCare staff: ________________________________

Patient # ________________________________

Community PedsCare is a palliative and hospice program for children with life-limiting and life-threatening conditions and their families. Established in 2000, it is a program of Community Hospice of Northeast Florida in collaboration with Wolfson Children’s Hospital, Nemours Children’s Clinic and the University of Florida-Jacksonville, bringing comfort and enhanced quality of life to the youngest members of our community.

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COMPONENTS OF A BIRTH PLAN WHEN THE BABY HAS A LIFE-THREATENING CONDITION

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Establish shared understanding of the information

“What is your understanding of babies with __________?"
“Tell me what your understanding is of babies with _______ and the likely outcome?”
“Most babies with__________ live _______ to _______ days/weeks/months. The chance of stillbirth is/is not increased. There are some things about your baby that make it likely that your baby may live longer/shorter. However, each baby is unique. While we don’t know exactly how long he/she will live, we will work with you to make sure the time he/she lives will be comfortable and meaningful to you.”
“I hear you say that you want us to ‘do everything.’ We will do everything that is helpful, is consistent with your goals, and will not prolong suffering.”

Goals of care

“As you think about the time that _____ might live, what is important to you?”
“Most families tell me that comfort, preventing suffering, spending time with the family, and helping their baby function well are very important. Are some or all of those things important to you?”

Site of delivery

“Have you thought about whether or not you want to deliver here or at _________ (community hospital)? If you want to deliver in the hospital near you so you are closer to your support, I will be happy to talk to your pediatrician to see if I can be helpful.”
“Because of uncertainty as to diagnosis/prognosis/symptom management needs and how long _______ might live, I recommend delivery at _________ (tertiary center with NICU) so that the newborn specialists can assess and manage him/her until we have more information about the probable outcome.”

Fetal monitoring: yes or no

Mode of delivery

“Have you talked to Dr. ________ about whether or not a Cesarean delivery would be considered if your baby is in distress?”
“Because a Cesarean delivery would put you at risk and would not help your baby, we recommend that you deliver vaginally unless there are maternal reasons for a Cesarean. What are your thoughts?” Or “I understand that it is extremely important to you to spend even a few minutes with _______ when he/she is alive. There is a moderate chance that your baby will die during labor. We are willing to do a Cesarean at term in the event of fetal distress if, after considering the risks and benefits, this is what you desire.”

• Who will be in attendance
• Management of the mother during the pregnancy, labor, and delivery
Children’s Project on Palliative/Hospice Services

- Maternal and neonatal medications
- Specified components of resuscitation

“Consistent with your primary goals of keeping _______ comfortable and minimizing suffering, I recommend that when she/he delivers, we have the NICU team there to assess. They could provide stimulation, suction, and oxygen for comfort. But I recommend against breathing for ______ or doing chest compression or giving medications as these are not likely to be helpful and will prolong suffering. What are your thoughts?” Or

“We know that ________ is likely to have many problems. You have requested that, because of the somewhat uncertain outcome, we do a trial of treatment. Therefore I recommend that the NICU team be in the delivery room. They can breathe for ________ if necessary and will provide a trial of treatment lasting ________ in the NICU. We will continue to make sure that she/he is comfortable during this time. What are your thoughts?”

### Site of care of the baby – mom’s room, NICU, home

### Feeding plan

“Most babies with ______ will not suck and swallow well. There are two acceptable choices and different families may choose either one and feel that they have made a loving decision. Some families choose to artificially feed via tube as they feel that this is not too burdensome and they are willing to learn to do this at home to spend some time with their baby. Other families, understanding that the poor suck is part of the baby’s condition, wish to let nature take its course and let the baby take whatever he/she can from breast/bottle. From what we understand going without food and hydration is not uncomfortable. Do you have questions about this? Do you have a preference? Do you need more time to think about this?”

### Baptism, ceremonies desired

“Are there special/important rituals in your family/culture/religion that you would like us to facilitate?”

- Special memories & mementoes
- Contingency post discharge plan – See the Neonatal Advance Care Plan
COMPONENTS OF A NEONATAL ADVANCE CARE PLAN

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This is not intended to be directive. Rather, these components are issues that most families benefit from addressing. It is not necessary to address all issues with all families or all issues at the same time. Adapt this to the needs of the baby and family, and to the course of the disease/condition.

<table>
<thead>
<tr>
<th>Goals of care</th>
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<tbody>
<tr>
<td>“As you think about the time that _____ has left, what is important to you?”</td>
</tr>
<tr>
<td>• “Most families tell me that comfort, preventing suffering, spending time with the family, and helping their baby function well are very important. Are some or all of those things important to you?”</td>
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<thead>
<tr>
<th>Medical issues</th>
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<tr>
<td><strong>Diagnosis and prognosis</strong></td>
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<tr>
<td>“Tell me what you understand about ______ problems and the likely outcome.”</td>
</tr>
<tr>
<td>“This is what we know about other babies who have the same issues as ________. Similar babies live about ______ to _______ days/weeks/months. While we don’t know exactly how long your baby will live, we will work with you to make sure the time with your baby will be comfortable and meaningful to you.”</td>
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<tr>
<th>Providing education and supplies</th>
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<tbody>
<tr>
<td>1. List members of the health care team and their contact information (table).</td>
</tr>
<tr>
<td>2. Identify what signs or symptoms should trigger a call to a health care provider: whom to call and when (may be table format).</td>
</tr>
<tr>
<td>3. Provide guidelines for pain and symptom recognition and management: What symptoms do you expect and what management would you provide if needed?</td>
</tr>
<tr>
<td>4. Provide supplies and/or prescriptions as needed – actually having the medication is less important if the family has a 24-hour pharmacy and a prescription.</td>
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<tr>
<td>5. Create or review nutrition and hydration status and plans.</td>
</tr>
<tr>
<td>6. Provide anticipatory guidance about signs of impending death.</td>
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</table>

“For most babies with this problem, when they get close to death they show it by ____________. The things that you might want to do to comfort them include ________________. The person you should call to support you and __ is ________.”

<table>
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<tr>
<th>Likely response to resuscitation</th>
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<tr>
<td>Give clear information about the likely response to resuscitation.</td>
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“If ________ has trouble breathing from secretions or airway problems, he/she might respond to ______. However, if your baby has increasing breathing pauses not responding to gentle stimulation, this is likely from the underlying condition and will not improve with resuscitation.”
Resuscitation status, what should be provided and forgone

“To summarize our discussions about your wishes, if ________ has breathing or heart rate problems that don’t respond to gentle stimulation, we will continue to provide intensive comfort measures but we will not intubate or ventilate ________ because they will likely be unsuccessful (or will merely prolong dying).”

Completion of POLST, hospital DNR form
Check with your own state about how to complete the POLST forms and where they should be kept. Ensure that the forms are disseminated to all caregivers and are accessible in case of emergency.

Preferred setting of care and death
Ensure that adequate resources are in place if family wishes the baby to die at home.

Other medical treatments: symptom relief, routine preventative care
Specify which treatments are to be done and which are not consistent with the goals of care. Some medical treatments such as oxygen, suctioning, and transfusions can be used as comfort measures and not specifically to prolong life. Address issues such as heart rate, respiratory monitoring, and lab tests such as newborn metabolic screening, bilirubin levels, diagnostic interventions such as cord blood or fibroblast samples, DNA banking

Community services
Use of community services such as home nursing or palliative/hospice care are highly recommended in all situations, but especially if the baby will die at home.

Family support

- Psychosocial, emotional, and spiritual support for family, including siblings – child life consultation can be especially helpful with respect to counseling siblings.
- Consultations – genetics, other pediatric subspecialists, chaplain, social worker, child life
- Financial/insurance issues – families can be coached in dealing with insurance companies to be advocates for their baby’s needs
- Memories, mementoes, photographs (Now I Lay Me Down to Sleep http://www.nowilaymedowntosleep.org/)

“How would you like to remember ________? Some families plant a tree, get hand and foot molds, hold Christmas in August, make a quilt… Can we help you with any of these?”

- Continuity of care over time and across sites of care and providers
  - Written advance care plan signed by provider and parents
    - Ensure that the form is disseminated to all caregivers and is accessible in case of emergency.
  - Plan for regular updates of goals and treatment plan

“We will plan to meet again in two weeks to discuss ________’s condition and whether or not the goals or plans need to be changed. If _____ or ________ happens, it is signaling that things are getting worse and we should revisit the goals and plan. Of course, if ________’s condition changes, we can meet earlier.”

  - Communication plan concerning disseminating preferences to current and potential care providers
  - Contact information for hospital- and community-based providers
Indications and method for contacting preferred providers

- Plan for emergencies
  - Do you call Emergency Medical Services? Team may need to call the EMS district to ensure that they can respect family wishes, especially if the family wishes to allow a natural death. It may be possible to get an alternative number to 911 to arrange for transport (but not resuscitation) if needed
  - If not EMS, whom do you call in event of an emergency?

- Logistics at time of death – if death is near, it is helpful to have a plan in advance
  - Who will declare death? Whether or not a home nurse or hospice nurse can declare death at home varies from state to state
  - Body care, rituals, transport of the body

“Some families find that having the funeral director come into the house to take the body is disturbing to the siblings. They prefer that one of the parents take the body out to the waiting hearse. What are your thoughts?”

“Would you like to bathe and dress _______?”

“Are their things that are important in your culture/religion when ________ dies?”

- Responsibility for contacting coroner/medical examiner/health care providers – in many situations, this can be done by the home nurse or hospice nurse, thereby avoiding the police coming to the house
- Preferences regarding autopsy
- Feasibility and preferences regarding organ/tissue donation – in many areas, contacting the organization is mandatory as death is imminent

“I have contacted the regional organ donation organization. They tell me that babies like ________ can usually donate __________ (organs, tissues). Is that something that you would like more information about? Do you think that you would like to donate ________’s organs/tissues when he/she dies?”

“Because of ________’s weight (or diagnosis), she/he is unfortunately not eligible to donate. However, your interest in this shows great generosity.”

- Burial or cremation
- Funeral arrangements and/or memorial service

- Use Resolve Through Sharing protocol for bereavement follow-up support. Hospices have a regular follow-up schedule of post-death contacts.
WHAT ARE THE OPTIONS FOR ORGAN AND TISSUE DONATION FOR A BABY WITH A LIFE-THREATENING DIAGNOSIS?

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For over four years I was the organ/tissue donation liaison at my hospital facility. When I began my role, I quickly learned that the public, and even some professional caregivers, had many misconceptions about organ and tissue donation. One misconception that could hinder a person’s decision to become an organ or tissue donor is this: When a patient presents to the hospital in critical condition, organs can be recovered even if the patient has not been declared dead. This is not true. The Uniform Determination of Death Act (UDDA) allows for recovery of organs from a person who is determined to be brain dead or has died from irreversible cessation of all circulatory and respiratory functions (Peabody, Emery, & Ashwal, 1989). Organ Procurement Organizations (OPO) have processes in place for living donors. The purpose of this article is to explore organ and tissue donation as an option for families whose baby will die or has died.

There are two ways to donate organs after death; both of which require patients to be on a ventilator before their death and organ recovery. The most recognized way to donate is when a patient is declared brain dead. Diagnoses that may progress to brain death include, for example, trauma, stroke, or anoxic brain injury that leads to severe brain swelling. There are strict criteria and tests to determine brain death. Declaration of brain death is the legal time of death. The patient who is brain dead remains on a ventilator with a heartbeat until the organ recovery takes place.

The second way to donate organs is known as donation after cardiac death (DCD). The patient has been given a grim diagnosis and the family and physician have made the decision to discontinue life-sustaining therapy, which includes the ventilator. In a controlled setting, the patient is extubated. If the patient’s heart stops beating within a specific timeframe and death is declared, organs can be recovered after an additional 5-minute waiting period. Waiting 5 additional minutes ensures there is no auto resuscitation of the heart. Because of these very strict criteria, babies with life-threatening diagnoses are not generally eligible to donate organs.

Questions arise about whether organs from babies who are anencephalic can be recovered to save the lives of other babies. Babies with anencephaly who are born alive have brain stem function, so they do not meet the criteria for brain death. They are living, breathing babies. In 1989 researchers at Loma Linda University conducted a study to determine whether babies with anencephaly who were placed on a ventilator at birth would be more likely to be eligible to donate organs than those who were placed on a ventilator only when they showed signs of imminent death. This study determined that placing these babies on a ventilator at birth did not result in more transplantable organs, and this practice is not utilized today (Peabody et al., 1989).

Babies with life-threatening diagnoses have the potential to be tissue donors through heart valve donation. A baby does not need to be on a ventilator in order to donate tissue. Each tissue recovery agency has specific criteria for donation, and because these criteria vary, each hospital and hospice needs to know the criteria specific to their regions. The agency with which I worked required that a baby be 34 weeks gestation or greater and weigh at least 6 pounds to be a candidate for donation. Tissue donation can be possible for a baby who is stillborn if fetal heart tones are documented 8 to 10 hours before birth and if the heart valves are recovered within the specific time frame allotted by the recovery agency.
Two babies' lives can be saved by the gift of donated heart valves. Families need to know that in order to determine whether the baby meets donation criteria, the mother's blood will be tested and that she will be interviewed about her medical and social history by a member of the recovery agency. They will also need to know that their baby may need to be cooled within 12 hours of death and that recovery must take place within 24 hours of death. Because the entire heart needs to be recovered in order to excise the valves, staff needs to prepare parents for a U-shaped, sutured incision site on the baby's chest after the surgery. The family may spend additional time with the baby after the surgery, and they may still choose to have an open casket at their baby's funeral. Donor families incur no charge for either organ or tissue donation.

During my time as the donation liaison, I worked with three families who expressed interest in donating their dying child's heart valves. The first family—after discussing options with the physician, tissue bank, and meeting the initial criteria—decided they would donate their baby's heart valves after his death. They were able to take their baby home and spend several hours with their family before he died. After his death, they chose to return to the hospital fairly quickly to begin the donation process. They had the option to spend additional time at home before returning but for them returning quickly was the right decision. They had the opportunity to spend more time with their child after the surgery. The second family asked to begin the screening process while the mother was still pregnant with her baby. Unfortunately, the mother's history excluded the baby from the possibility of donation. The third family had a baby who was being discharged from the newborn intensive care unit with a life-threatening condition. Because this family lived in another state, I explained the process to the family and initiated a phone consultation with the closest hospital in their state, but I did not participate in their final decision making due to the change in hospitals.

The opportunity for donation is rare for babies with life-threatening diagnoses. There are many reasons that parents choose donation. These may include: (a) the desire to help another child, (b) wanting someone to donate for them if that were possible, (c) believing it is the right thing to do, (d) feeling that their child lives on in another, (e) religious reasons, and (f) having personal experience with donation in the past (Weiss, Fortinsky, Laughlin, Lo, Adler, Mudge, & Dimand, 1997). The families with whom I worked felt that donation was one more way to honor their child and to create part of their legacy. I was always in awe of parents who chose donation. How difficult it must be to say goodbye to your beloved baby while making the decision to give life to a complete stranger.

References

PROFESSIONAL AND PARENTAL RESOURCES FOR PRENATAL/PERINATAL PALLIATIVE & HOSPICE CARE & INTO BEREAVEMENT

Compiled by Ann Fitzsimons, BS, MBA
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As this newsletter has attested to, there has been an explosion of insights and resources in recent years relative to caring for the parents and babies with prenatal diagnoses which may be incompatible with life. The underlying premise behind many of these learnings is that families should be allowed to have choices as to what this journey looks like for them—to carry life even in the face of death, to allow death to happen naturally, or whatever else they may choose for their baby. However, the professionals caring for them may not be aware of all the resources available to them, as caregivers, as well as what’s at their fingertips to point these families to in terms of parent/family resources.

What follows is a brief listing of some of the leading organizations and resources in the field of prenatal/perinatal hospice and bereavement, which often have both professional and parental resources available on their websites. It is our hope that these will help the professionals who care for these families and their babies to learn how to do it better, in addition to now having resources they can make available to the families during their journeys with their babies, so as to empower them in making the best decisions for their baby and their entire family.

Note: Much of this information on these organizations/their resources has been taken directly from each organization’s own website.

**Perinatal Hospice & Palliative Care Resources**

**Perinatal Hospice.Org**
- A clearinghouse of information about perinatal hospice and palliative care, edited by Amy Kuebelbeck, a nationally-known speaker and writer on the subject. This is one of the most comprehensive websites on prenatal/perinatal palliative and hospice care, offering a plethora of resources to parents and healthcare providers/perinatal hospice advocates for when the family has received a prenatal diagnosis that indicates the baby will likely die before or shortly after birth.
- Resources include, but not limited to:
  - Comprehensive list of perinatal hospice/palliative care programs and support in the US and internationally (updated continually as new programs become available)
  - Topic-related medical journal articles and professional resources for caregivers (e.g., training videos, perinatal palliative care toolkits, presentations, links to other organizations’ resources in prenatal/perinatal palliative and hospice care, birth and parenting plan templates, etc.)
  - Resources for families (e.g., books, brochures, helpful information on birth planning, FAQ’s, etc.)
- Website: [www.perinatalhospice.org](http://www.perinatalhospice.org).
- Facebook page: [http://www.facebook.com/PerinatalHospice](http://www.facebook.com/PerinatalHospice).
- Amy Kuebelbeck can be contacted through the website or at [info@perinatalhospice.org](mailto:info@perinatalhospice.org).

**Bereavement-Related Resources**

Gunderson Lutheran Bereavement Services
Bereavement Services offers bereavement education, consultation, and support materials and is best known for its Resolve Through Sharing (RTS) program.

RTS was founded in 1981 and has led the field in perinatal bereavement education for professionals who care for families when a baby dies from miscarriage, ectopic pregnancy, stillbirth, and in the newborn period. Today, more than 30,000 professionals have been trained in the RTS approach.

Some of the resources for perinatal care or perinatal hospice include a Perinatal Palliative Care Toolkit, the brochure Waiting for Birth and Death: Knowing Your Baby Will Not Survive, a position paper, and an annual workshop entitled Blueprint for Perinatal Palliative Care Program®.

Other professional resources include:
- Conferences, Workshops, Webinars, & Online courses relative to Perinatal Death and Bereavement
- Publications
- A catalog listing a wide range of helpful materials for bereaved parents and the professionals who care for them—e.g., Nurses, chaplains, social workers, physicians, genetic counselors, mental health providers, childbirth educators, doulas, funeral directors, etc.

Contact information:
- Bereavement Services, 1900 South Ave., Mailstop ALEX, La Crosse, WI 54601
- Phone: 608.775.4747 or 800.362.9567, Ext. 54747
- Website: www.bereavementservices.org or berservs@gundluth.org

Pregnancy Loss and Infant Death Alliance (PLIDA)
- PLIDA was organized in September, 2002, by professionals dedicated to providing support to parents grieving the death of their baby or babies during pregnancy, delivery, or infancy.
- Mission: 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.
- PLIDA does this through:
  - Providing opportunities for members to share support, resources, and information on implementing the highest standards of perinatal bereavement care
  - Developing and maintaining educational resources for members only, along with a members-only networking space
  - Collaborating with allied organizations
  - Producing position statements on the emotional aspects of perinatal bereavement care in clinical settings
  - Producing practice guidelines that illustrate relationship-based bereavement care
  - Sponsoring a biennial international conference
- Position Statements include:
  - Infection Risk
  - Pathology Studies
  - Bereaved Parents Holding Their Baby
  - Offering the Baby to Bereaved Parents
- Contact information:
  - Website: www.plida.org

Share Pregnancy an Infant Loss Support, Inc.
- Mission: To serve those whose lives are touched by the tragic death of a baby through pregnancy loss, stillbirth, or in the first few months of life.
- Their primary purpose is to provide support toward positive resolution of grief experienced at the time of, or following the death of a baby. This support encompasses emotional, physical, spiritual, and social healing, as well as sustaining the family unit.
Their secondary purpose is to provide information, education, and resources on the needs and rights of bereaved parents and siblings (see these included elsewhere in this newsletter with permission). Their objective is to aid those in the community, including family, friends, employees, members of the congregation, caregivers, and others in their supportive role.

Their professional resources include, but are not limited to:
- How to start a Share Program
- Training & Conferences
- Helpful Hints for Caregivers
- Professional Partnerships
- Memorial Planning, Funeral and Memorial, and Other Resources
- They provide free resources to all bereaved parents and their loved ones, including brochures to help educate the parents and those supporting them

Contact information:
- National Share Office, 402 Jackson Street, Saint Charles, MO 63301-3468
  - Phone: 800.821.6819
  - Website: www.nationalshare.org
While a great deal is known about adult palliative care, particularly for those suffering from cancer, there is not enough knowledge about how children who have untreatable illnesses feel in Norway. And the differences and variations in the diagnoses of these children are huge. Many children are unable to talk; some are blind or deaf and have enormous challenges communicating. These children require extra help from those around them, health workers, families, doctors and other professionals. They need help to see, listen, and touch, and for someone to just BE there.

Andrea, who was my mentor and daughter, is the child who is responsible for the founding of “Yes to Palliative Units and Care for Children in Norway”; she died in our bed, February 7, 2010, aged 17 years. The idea for such work grew in me throughout this process over many years, struggling and fighting for best care and service. And of course the lack of PPC. Following many of my own experiences as a parent, a previous health-worker, and a priest, I have observed that there is a lack of assistance for a large and unknown group of children and their families who needed PPC. We do not know what tomorrow brings, and being fortunate to have been a mother for 17 years to a child with multiple handicaps who lived with one foot in the grave, I have experienced this fact with mind, body, and soul. I have experienced unnecessary suffering and stress simply due to a lack of knowledge. To provide a worthy and dignified end-of-life care for a child’s life is very difficult as the fear of the unknown is always there! A child’s death will always be difficult, but without knowledge and support, it becomes far more difficult than it needs to be. And in Norway there is a very strong focus on curative medicine. There are only three hospices for adults and none for children in the country. That we hope to change.

Palliative care is a new field in Norway. And it has only been for adult patients with cancer for the last 15 years. Until 2009, Pediatric Palliative Care (PPC) for children with life-limiting (LLC) and life-threatening conditions in Norway had no attention. In three years, this field has now received considerable attention from political leaders and more widely in the Norwegian society; this has lead to activity in several areas. The founding of “Yes for Palliative Units and Care for Children in Norway” is the first organization in the Nordic countries working for PPC and advocating for this, has led and contributed to this development.
The very same day that Andrea was buried, our government finally talked about a “Plan to Help Living,” which occurred on March 2, 2010. In December 2011, the Committee on Health and Care Services acknowledged the need for improving the response for children in need of PPC and a unanimous Storting (the Norwegian Parliament) decided that Norway should develop national guidelines for children with palliative care needs. The Storting is the supreme arena for political debate and decision-making in the Kingdom of Norway. It represents the ultimate expression of the sovereignty of the Norwegian people. Through the Storting, it is the people who govern the country, introduce legislation, authorize public spending, impose taxes, and control the work of the Government.

In February 2012, the Norwegian Ministry of Health and Care Services, gave the Norwegian Directorate of Health the mission to make guidelines for PPC. Several times our organization has been mentioned in the Norwegian Parliament. In a very short time, we have accomplished a lot although there is much more to achieve. But we will succeed.

The methods we used included a variety of approaches to raise awareness and promote the need for action: these included using social media, media, collaborations with political parties and politicians and partnership working with other health professional organizations both internationally and nationally, articles in different journals, a conference, and giving statements to several public hearings to Storting.

Our results and achievements: Developing guidelines for PPC in Norway; holding the first conference on PPC in the Nordic region; mobilizing increased attention, political advocacy, and influence. Our plans for the way forward are to recognize the need to get PPC into the education system and to ensure that the standards for pediatric palliative care in Norway apply the principles of WHO’s definition of pediatric palliative care. The Government needs to commit to sustained adequate funding to provide holistic, multidisciplinary palliative care in a variety of settings, including home, schools, hospital, and respite care settings, and to meet this need in the future.

I have had a lot of help from Together for Short Lives (the former ACT), CHI, and ICPCN. And I’m also in ICPCN’S advocacy group working for PPC global.
Items of Interest
In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. Pediatric Continuum Briefing Available. NHPCO’s Mary J. Labyak Institute for Innovation is pleased to offer a pediatric-focused continuum briefing, Pediatric Concurrent Care (PDF), available free of charge online. The goal of the continuum briefing is to help providers work together to assure that each state’s most medically fragile children have the quality care they deserve. The document provides:

- Definition of pediatric palliative and/or hospice care;
- An overview of Concurrent Care for Children provision in the Affordable Care Act (ACA);
- Identification of the barriers for pediatric palliative care that are not addressed even with the provision for concurrent care in ACA;
- Key strategic opportunities for hospice and palliative care providers to expand the care continuum for children living with life-limiting or life-threatening conditions and their families.

2. New Pediatric Care Module Available on E-Online. The newest module in the 10 module training series on pediatric palliative care is now available on NHPCO’s E-Online education portal. Be one of the first to sign up for the latest module in the series that is designed to furnish you with the latest trends in pediatric palliative care provision.

- Module 7: Pediatric Palliative Care - Symptom Management - This module provides pediatric palliative care practitioners with state-of-the-art information about symptom management.

As a reminder, here are the other modules in the Pediatric Palliative Care series:

- Module 1: Principles and Standards
- Module 2: Delivery Models
- Module 3: Ethics, Decision-Making, Advance Care Planning
- Module 4: Childhood Development in Health and Illness
- Module 5: The Spectrum of Complex, Chronic and Fatal Conditions in Pediatric Palliative Care
- Module 6: Assessment and Management of Pain

3. A Video Link. Readers who were interested in the “Summer Camp” article by Scott Newport in the ChiPPS Newsletter, Issue #28 (August, 2012) of this newsletter, will be interested to click on the following link which provides a video version of the same imaginative way in which parents can memorialize a child with a life-threatening illness.

https://vimeo.com/47821223

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics
4. CTC CALL FOR PEDIATRIC SESSIONS PROPOSALS. “There is a way to do better – find it,” wrote Thomas Edison. To Mr. Edison’s words, we would add: Create it, develop it, practice it, measure it, expand it, claim it, partner with it, share it, advance it! The theme for NHPCO’s 14th Clinical Team Conference and Pediatric Intensive underscores a drive for the hospice and palliative care field to innovate and pursue excellence in all endeavors. A key component of the conference, of course, is the Pediatric Intensive.

Pediatric palliative and hospice practitioners that can add to the rich array of advanced level topics in pediatric and palliative care and hospice are encouraged to join colleagues from across the country that are committed to innovation and excellence by submitting a proposal that demonstrates significant work and achievement for NHPCO’s 14th Clinical Team Conference and Pediatric Intensive: Innovation and Excellence, to be held from September 26 – 28, 2013 in Kansas City, Missouri. The deadline for proposals is March 25, 2013.

The Conference Planning Committee is particularly interested in receiving proposals for advanced (for the expert) topics. Although all professional disciplines will be represented in the educational content and interdisciplinary team practice is a key focal area, psychosocial and spiritual topics in particular are being sought. Help ensure that hospice and palliative care professionals have the knowledge to ensure the provision of quality care now and into the future by submitting a proposal today!

5. THE 2013 INTERNATIONAL CONFERENCE ON PERINATAL AND INFANT DEATH. The 2013 conference, “Partners in Prevention, Research, Advocacy and Support,” will be held in Minneapolis, MN, on April 18-21, 2013. The conference is sponsored by the Association of SIDS and Infant Mortality Programs and Pregnancy Loss and Infant Death Alliance. Consult the website www.perinatalbereavementconference.org for early registration by March 8, 2013 for reduced rates.

6. PEDIATRIC BIOETHICS WEBINAR SERIES. Dr. Brian Carter (now at UMKC, Children’s Mercy Hospital & Clinics in Kansas City, MO) has announced a free registration for a new CMH Pediatric Bioethics Webinar Series. Email bscarter@cmh.edu for additional information.

7. PEDIATRIC GRIEF SONG NOW AVAILABLE. Grammy award winning song writer, Joanne Shenandoah, was inspired by what she experienced at a children’s grief camp her daughter was attending after the death of a dear friend. She wrote the song, ‘I Feel Your Love,” to help others heal. Joanne would like to graciously share this song with all hospice and palliative care providers that might find this to be a useful piece of music for their work. Watch the video of “I Feel Your Love” on YouTube – and consider sharing it with those you are working with and are supporting. Our appreciation goes out to Joanne for sharing this song with the hospice palliative care community.

http://youtu.be/76GWcGi4lpM
8. SIXTH ANNUAL PEDIATRIC PAIN MASTER CLASS. The Children’s Institute for Pain and Palliative Care (CIPPC), Department of Pain Medicine, Palliative Care and Integrative Medicine, will offer its 6th Annual Pediatric Pain Master Class on June 1-7, 2013, in Minneapolis, MN. Registration is limited. This course has filled each year. Interested parties are encouraged to complete their registration early to secure their spot. The deadline for registration is April 30, 2013, or when full. Registration fee of $2,500 includes registration, course materials, continental breakfast and lunch Sunday through Wednesday and Friday, plus coffee/tea breaks, a reception on the first evening and a catered picnic in Minneapolis. Online registration and payment is available through: childrensMN.org/conferences. Accommodation and class venue: Marquette Hotel, 710 Marquette Avenue, Minneapolis, MN 55402, U.S.A., www.marquettehotel.com. Rate: $175/night. Take advantage of these special rates for the CIPPC Pain Master Class by booking your hotel reservation by midnight on May 1, 2013.

9. NHF GALA SPONSORSHIP OPPORTUNITY TO HONOR PEDIATRIC CARE. The 2013 National Hospice Foundation Gala, held in conjunction with NHPCO’s 28th Management and Leadership Conference, will embrace those at the center of our care – the patients and families we serve. This year’s gala will pay special tribute to the youngest in our care, our pediatric patients. During our celebration, we will honor these heroic patients and those who love and care for them. A special opportunity will be available to honor hospice and palliative care providers, individual professionals, caregivers and champions who provide extraordinary care and supportive services for children and those who love and care for them. From direct care to patients, through grief support for families, please join us in honoring these outstanding champions who provide pediatric care services. Learn more about this special opportunity to honor a colleague, organization, supporter, family or patient!

10. SUBJECTS AND CONTRIBUTORS FOR FUTURE ISSUES OF THIS NEWSLETTER. In past issues of this newsletter, we have addressed a wide range of subjects, including bereavement, complementary therapies, examples of programs illustrating the current status of pediatric palliative and hospice care in the United States, memory building and legacy making in pediatric palliative and hospice care, examples of programs offering this type of care in various parts of the world outside the United States, ethical issues related to pediatric palliative and hospice care, help and healing in relationship to bereavement perspectives, stress and moral distress (identifying stressors and supporting staff), using social media and electronic communications to network by families and practitioners, the role of pediatric palliative and hospice care in creating systems to support children, families, and the community, children are not little adults (i.e., respecting differences in providing pediatric palliative/hospice care), and honoring volunteer perspectives in pediatric palliative and hospice care. (Please note that you can visit archived issues of this newsletter at nhpco.org/pediatrics.) For future issues, we are thinking about addressing subjects such as pre-natal pediatric palliative/hospice care. If you know of good topics and/or contributors (including yourself) for any of these and/or other future issues of this newsletter, please do not be shy! Step right up and contact any of the following: Christy Torkildson at christytork@gmail.com; Maureen Horgan at Horgan.Maureen@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

11. READER’S CORNER. Our Reader’s Corner column provides brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric palliative care, but that may not be known to all readers of this newsletter. We welcome suggestions for publications to include in our Reader’s Corner and/or summaries and comments on such articles following the model in this issue. Please send all such suggestions to Christy Torkildson at christytork@gmail.com.
12. CALENDAR OF EVENTS. As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, nhpco.org/pediatrics. ChiPPS is a program of the National Hospice and Palliative Care Organization. Please e-mail Christy Torkildson to have your pediatric palliative care educational offering listed.

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

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, the Solutions Center will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the ChiPPS Web page at http://www.nhpco.org/pediatrics for further materials and resources of interest.