Advance Planning in Pediatric Hospice/Palliative Care, Part One
Issue #38; February 2015

ChiPPS E-Journal

Children’s Project on Palliative/Hospice Services
Released in collaboration with the National Hospice and Palliative Care Organization

National Hospice and Palliative Care Organization
1731 King Street, Alexandria, Virginia 22314
www.NHPCO.org/pediatrics
Welcome to the 38th issue of the ChiPPS E-Journal (formerly, the ChiPPS electronic newsletter). This issue of our E-Journal offers a PDF collection of articles that explore selected issues in advance planning in pediatric hospice/palliative care. These articles argue for the value of advance planning, describe tools for that purpose, explain how to initiate advance planning conversations, and indicate who should be involved in this care. Because this is a very important subject, we have decided to devote two issues to these discussions. Even so, we appreciate that no two issues or collections of articles will do justice to these broad topics, but we hope that the articles in this issue and in the one to follow will spur discussion and implementation of advance planning as a cooperative enterprise with children, adolescents, their family members, and the professionals involved in their care. We welcome communications from anyone who has more to offer on these subjects.

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

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

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

**One Last Gift**
Scott Newport
We often refer to Scott Newport as our "resident poet" and we frequently print his poems in this E-Journal. In a change of pace, however, we begin with an essay by Scott that describes an encounter with another bereaved parent who was searching for one last gift for her son the evening before Christmas.

**The Missed Opportunity:**
*A Professional’s Reflection on Advanced Care Planning and “The One”*
Holly Davis, MS, APRN, and Jennifer Holler, LCSW, ACHP-SW
This article describes lessons learned from the one youngsters who sticks in a professional’s mind. He was an adolescent who was her first palliative care patient. The lesson is her realization in looking back that she had failed to initiate a conversation with him in which he could share his wishes before his death.

**Perinatal Advance Care Planning**
Carol May RN, MSN, MBA, CHPN
This article describes a program that engages in advance care planning in perinatal situations and argues for the value of such planning.

**Value-Centered Care: Supporting Family Decision-Making with a Narrative Approach**
Jeff Beck, MD
This article argues for the advantages of employing a narrative approach in discussions with the parents of a newborn with multiple complications in order to identify the values that are most important to them in the care of their daughter.

**Implementing Advance Care Planning and Utilizing Advance Care Planning Tools**
Suzanne S. Toce, MD
Given the availability of multiple advance care planning tools, this article identifies the components of an ideal tool for such planning, while recognizing that any tool or document used for this purpose should be individualized according to the needs of the child/family. The article next describes who should be involved in an advance care planning conference, when it should take place, and what the process might look like. The article concludes with a brief list of questions to ask about advance care planning tools.

**Courageous Conversations:**
*Implementing Advance Care Planning with Adolescents and Young Adults*
Sima Zadeh, PsyD, Maureen Lyon, PhD, ABPP, and Lori Wiener, PhD, DCSW
Drawing on their research with adolescents and young adults, the authors describe the development of the *Voicing My CHOiCES™* document, an advance care planning document specifically designed for this age group. They also explain how advance care planning documents should be used and argue that pediatric advance planning models should be incorporated as standard of care.

**The American Academy of Pediatrics (AAP) Statement on DNR in the School Setting**
Suzanne Toce, MD
In this open access article, you will find a review of available data on DNR policies in the school setting, general lack of supporting local and state regulation, and suggestions for an action plan that should accompany any advance care plan including withholding non-beneficial resuscitation.

**Items of Interest**
In each issue of our ChiPPS E-Journal, we offer additional items of interest.
As a remodeling contractor and a regular visitor to Home Depot, I have become an expert of sort; that is, of noticing the difference between a wandering homeowner and a Carhartt-wearing building trades guy. This past Christmas Eve was no different.

“Hey ma’am, lookin’ for that last special gift for your husband?” I asked.

Her back was to me and for the last minute or two I had noticed her spinning almost like a ballerina on a cloud-filled stage searching for a magical moment to appear. Instead of a stage though, she was twirling in the center isle of the big box store which was nearing closing time.

All that seemed to remain within her reach were low volume, holiday specials, ruffled ribbons, and untied bows sagging off cardboard, end caps. There were also a few wondering sales associates who I assumed would rather have been at home.

She then turned toward me and replied, “No, I was wondering if there are any books here for making small projects. My son loves to work with wood. I need to get him just one last gift. He doesn’t need any more of the electronic gadgets.”

After confirming with a few of the pro-sales guys, I know pretty well that Home Depot doesn’t sell books anymore. As I walked away from them my mind started to spin too. You see, I have been a carpenter for over thirty years and I love working with wood also. I just couldn’t imagine a young apprentice woodworker going without.

“I would just like to find a project he could build on Christmas morning,” she repeated again.

“I helped my 15-year-old son and his girlfriend build small bird houses last summer and that went pretty well,” I offered up. “Maybe the craft store next door has something.”

The lady didn’t reply so my mind sped up to full speed like an anxious elf in Santa’s shop just about to be let go for…… well, you know, for not doing his job.

“Eh, I got it, what about a small tool box?” I said.

“Yea maybe,” she hesitantly replied.

As we started to walk down the plywood isle I told her about my own Red Wood tool box I built and how I use it as a metaphorical teaching tool. I explained how I tell parents of sick kids after getting an initial diagnosis that they are like apprentices and they need a tool box to become an expert in their child’s care. I often do this at C. S. Mott Children’s Hospital.

The point of the box is to explain to the parents everyone at the hospital has a tool for them; health care is a team effort.

“The doctors, the nurses, social workers, all of them have their own specialties,” I told her. "It's not just one individual.”

I then encourage the family to start collecting these tools to help give the best care they can to their children.
Before I could say another word, she stopped right at the tool rental entrance, turned toward me, and said, “My daughter had brain cancer and she died on 9/11. As the twin towers in New York were crumbling that day my daughter slipped away from us.”

Shocked for a moment, I wondered what to say. So thinking it would be ok I said, “I had a son who died at a young age of heart disease.”

I don’t know if that is when the magic started to happen between Sandy and me but I think so.

When we finally made it to the section of pre-cut plywood, I helped her pick a piece of birch that was about 2ft by 4ft. As we continued to talk about our kids who had died, she told me how she works in the medical field but also has a nonprofit called, Allie’s Angels named after her daughter to help other families. [http://www.alliesangels.com/AboutAllie/Overview.htm](http://www.alliesangels.com/AboutAllie/Overview.htm)

“Scott, do you happen to know Paula Crosby up at Mott?”

Totally surprised, I said. “Sure, she and I are real good friends.”

Sandy then explained, “I met Paula on an on-line support, grief group. A few years back we agreed to meet in person.”

As we seemed to connect more and more with folks we both knew, I also started to think about how her family would make the tool box on Christmas day. I mean, I could just see them trying to cut the plywood with a dull handsaw passed down by grandpa.

Just as I was going to say goodbye, I saw Jeremy, one of the Home Depot lumber guys stacking ladders on a pallet getting ready to be shipped out.

“Hey Jeremy, could you cut this wood for this lady?”

Smiling, and without hesitation, he said, “Sure.”

“I know you usually cut larger pieces, but is there any chance you can cut small individual sizes so she can have a ready-to-assemble tool box?” I asked.

While Jeremy started to cut the pieces, I told Sandy we would need to get a one inch dowel rod for a handle and a drill bit to cut the hole.

As Jeremy handed each of the individual pieces to us the project seemed to be really coming together until the bottom didn’t quite seem to fit.

“Jeremy, can you take a ½ inch off this, I know this saw is not quite set up for that but…”

“Sure, Scott, that’s not a problem.”

As Jeremy got on his hands and knees and took his pencil and meticulously marked out the wood, I realized what Sandy had said about her son’s age. He was eleven. I couldn’t help but think about my own boy, Evan. He would be just about the same age today.

I even thought about if I needed that one last gift for my son and maybe even finding myself in a similar circumstance as Sandy on the eve of Christmas. You know, finding that one person who could help me fulfill my quest.

Before we left we exchanged contact information and her last words were about how she sees her daughter through special moments just about every day. She also told me how her son was born on the
same day as her husband’s birthday and how the one thing her daughter, Allie, loved the most was birthdays.

“There are so many times, that are way beyond coincidence I see my girl,” she proudly said.

I mentioned earlier in this story about how I thought maybe the magic of that Christmas Eve started when we connected in the lumber isle of a Home Depot. With two complete strangers sharing a common life experience of living through the death of a child.

Now that I think about it, the magic was really about when she told me how much her daughter loved birthdays. I now really think Allie gave both Sandy and me something special on the eve before we celebrate the birth of our Lord.

Allie gave us a bit of peace in a time, especially the holidays, when we parents often grieve the most and maybe Evan was there too. I sure hope so.

Thanks Allie and thanks Jeremy. Jeremy told me later how he had overheard Sandy and me talking about the death of our children before I gave him the dimensions of the wood. When I asked him how he felt he said, “Scott, I was only doing my job.”

Editor's note: For Scott's earlier description of the role of his toolbox, see issue #27 of this ChiPPS E-Journal (May, 2012; formerly called our E-Newsletter). You can find that issue and all previous issues at www.nhpco.org/pediatrics
Every healthcare professional who has ever worked with children has their “one” kid. The one child who sticks with you, who taught you more than you learned in school, who shaped your professional career, and even impacted your life more than you can adequately express. Maybe it’s the kid that you “saved”; or the child that made the miraculous recovery against all odds; or the one child that taught you to appreciate life’s greatest gifts. I would like to share my reflection on my “one child”—the one who shaped my professional career. He was the missed opportunity for me. The one I carry with me through every patient experience, each and every day.

Cody was an adolescent enrolled in our pediatric community-based palliative care program. Cody lived a very full life despite his diagnosis of Duchenne’s muscular dystrophy. He attended school, had friends, was involved in family life, and lived the life of a typical teenager despite his medical condition. He was a very sweet and feisty 16 years old, but he was completely bed bound and dependant on his family for his care.

Cody had been in the pediatric palliative care program for about 10 months when he started exhibiting the end-of-life signs that I now realize I missed. I was new to my role as a pediatric hospice social worker, and he was my first palliative care patient. With every visit, his condition had declined. The decline was barely noticeable at first; however, looking back on the situation, he had all the indicators. He was scared of what he knew was happening and worried about what he may not know as death came near. He had questions, fears, and anger; and there were countless missed opportunities to open that conversation door to explain to him what was happening. However, I was unprepared, and maybe even reluctant to allow the conversation to happen.

As death approached, our team worked closely with his mother, trying to prepare her for his death. I tackled her psychosocial suffering and helped her with final arrangements. His mother was adamantly that she did not want him to die at home because she was the one that “had to live here after.” Our nurse tried to help her see the big picture of Duchenne’s muscular dystrophy. He attended school, had friends, was involved in family life, and lived the life of a typical teenager despite his medical condition. He was a very sweet and feisty 16 years old, but he was completely bed bound and dependant on his family for his care.

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I recall sitting with him for hours, playing video games, laughing, and sometimes just sitting in silence. I feel now that he was waiting, waiting for me to ask him “How are you really doing?” or “What are you worried about?” There were times, looking back, when he made comments like, “I won’t be here,” or “You can have this, I won’t need it anymore,” that it is evident he had “given up.” I see now that his goals of care did not match the medical team’s goals of care. Cody wanted to be home, pain free and playing video games. He did not want to go to the doctor’s office or to the hospital, and he really didn’t want his wound dressing changed two times a day.
I carry Cody with me every day and use this learning experience to improve the care for every patient I encounter. I am an advocate of the use of Pediatric Advance Directives. I believe the advanced care planning conversation is just as important for children as it is for adults. Just as I was, many healthcare professionals are uncomfortable with starting the conversation. Yes, it is a difficult conversation, but it can be easy to have. Open the door by simply asking the child, “What do you think is happening?” I can almost guarantee that every chronically-ill child has either already heard something about their diagnosis or have done an internet search on it themselves; especially the adolescents. Children know something is happening inside their bodies and they are waiting on us (the adults) to open the door to the conversation. Pediatric hospice and palliative care professionals hear “we don’t want to tell him he’s dying” or “we don’t want him to lose hope if you say hospice” from parents and other healthcare professionals. In my experience, the exact opposite is true. The child already knows they are dying; they are just waiting for someone to be open to the conversation so they can share their fears, questions, and worries.

These conversations can be started by anyone. We don’t have to wait for the social worker or child life specialist to be available. Any one of us can open the door and give our patients the permission they may feel they need in order to share their feelings. Frequently, the child opens up to the healthcare professional first. With the support and encouragement of the healthcare professional, we can then begin the conversation with their parents and share the feelings, concerns, and fears everyone is experiencing, which then closes the circle. Imagine how great it would be if by encouraging these conversations, we could give the gift of peace to every family we touch?

Children want a chance to make their wishes known. If a child asks a question, most of the time, they are ready to hear the answer. By avoiding the topic or question, healthcare professionals miss a great opportunity to teach, share, and learn. Most children I have had the opportunity to work with since my experience with Cody have been able to plan their own funerals and decide who should get their prized possessions. Above all, each child wants to make sure that someone will take care of their parents when they are gone and cannot do it themselves.

There are great tools and resources available, such as “My Wishes” and “Voicing my Choices” produced by Aging with Dignity (www.agingswithdignity.org) and the Conversation Project (www.theconversationproject.org), to help start the conversation with a child. We, as healthcare professionals, simply have to be as brave as the children we serve and open the door to the conversation.
Do you have an advance care plan? Do your loved ones know what type of care you want at the end of your life or more importantly what you do not want? These are hard questions for adults to answer, but can you imagine how difficult this topic can be to discuss for expectant parents?

Pediatric palliative care programs are broadening their scopes of practice to include children who are not yet born. These children have been diagnosed with a life-limiting anomaly and may have a life expectancy of minutes, to hours, to days. Parents who decide to carry their babies to term have the opportunity to plan for their baby’s “life.” An advance care plan provides the parents, siblings, and family members the opportunity to focus on the baby and to allow their time together to be of good quality and comfort.

The Supportive Care Program at Children’s Hospital of Pittsburgh of UPMC developed a perinatal program in conjunction with the Fetal Diagnostic Treatment Center (FDTC) at Magee Women’s Hospital of UPMC. Once a parent makes the decision to carry the baby with a life-limiting anomaly to term, the parents are referred to the Supportive Care Program. The genetic counselor on the FDTC contacts the Supportive Care team and facilitates an appointment with the mother, at times the father or other support person.

The essential part of the meeting is to establish the goals of care for both the baby and the family, and to document these goals in an advance care plan. The advance care plan is documented in letter format and is provided to the mother (parents), OB, FDTC, the Neonatal faculty and pediatrician, if known.

The Supportive Care Team will assess the mother’s (parents’) understanding of the baby’s diagnosis and prognosis. It is important to assess what the mother expects will happen at the time of delivery. In most cases the mothers (parents) have already met with the neonatologist and have reviewed who will assess the baby in the delivery room and who will execute their plan of care for their baby. The neonatologist documents their visit in a letter form to the OB, NICU faculty, and Supportive Care Team.

The Supportive Care Team finds it essential to developing a rapport with the mother (parents), which leads to a comprehensive plan of care, by learning as much about the baby as possible and not just the diagnosis or prognosis. Mothers (parents) often have named the baby. Understanding how they came to that name and the meaning of the name is an effective way of understanding the mother’s (parents’) feelings. A name is a powerful way to give meaning to your child. Asking about siblings and what they know about the baby is also helpful in understanding the goals the mother (parents) has for the baby.

The Supportive Care Team will explain what they understand will happen with the baby based on the diagnosis and their previous experience with other babies. The clinical symptoms that the baby may experience are reviewed with the mother (parents). Based on the potential symptoms, medications and treatment plans are explained and decisions are made based on the mother’s (parents’) goals of care. Every family the team has met with is most interested in ensuring that “my baby does not suffer or experience pain.”

For example, the Supportive Care team met with parents of an expectant baby with Osteogenesis Imperfecta Type 1. The parents’ priority was to ensure their baby did not experience pain or suffering. The parents understood that the baby would have already experienced broken bones in utero and that the delivery process would result in more broken bones. As a result, they wanted to have a developed pain plan. The team reviewed the plan for sublingual morphine to be given at the time of delivery if and when the baby showed signs of pain. The parents were pleased to know the medication could be given sublingually and the baby would not require an IV, a procedure that would also cause pain and could
delay time until the baby was comfortable.

In addition to pain, other physical symptoms are reviewed and treatment plans are discussed by the Supportive Care Team. These symptoms include, but are not limited to, respiratory distress, agitation, and secretions. It is important for mothers (parents) to understand what they may see or hear with their baby in order to assist with coping and understanding of the dying process.

One of the most difficult parts of advance care planning for the perinatal population surrounds feeding. The MOST nurturing part of being a mother (parent) is to feed your child. The idea of not feeding because the baby is unable to feed does not seem “right” to a mother (parent); it is unnatural and often referred to as “starving.” It is important to review the clinical circumstances when a baby is both physically unable to feed and cognitively unable to recognize that he or she is not being fed. When the baby does not have the coordination to suck, swallow, and breathe, it is ethically acceptable to not offer artificial hydration or nutrition but often does not feel “right” to the mother (parent).

It is also important to assess the mother’s (parents,) emotional and spiritual needs. The team assesses if the mother (parents) is connected with a religious/spiritual organization and if a representative from that organization should be present at the time of delivery. In addition, it is important to assess any particular beliefs or practices that need to be followed at the time of death. If the mother (parents) are not affiliated with a particular organization and wants to have a member of clergy present, the team will contact the clergy department at the delivering hospital and arrange for a member of clergy to be present at the time of the delivery.

The Supportive Care Team will also offer additional resources including photography, provided by the organization Now I Lay Me Down to Sleep. The team will review the availability of music or specific lighting for the birth. It is also important to state what individuals the mother (parents) want to be present at the time of delivery, especially if the baby is not expectant to live longer than minutes.

If the baby is expected to live for a period of time and may be discharged from the hospital, a neonatal advance care plan needs to be developed. The care plan should include pain and symptom treatment plan, resuscitation status, and the preferred place of death. The Supportive Care team works with local hospices for mothers (parents) who want their child to die at home. For mothers (parents) who cannot imagine taking their baby home to the nursery set up for a baby who would survive, a sub-acute hospital is available to provide end-of-life care. The Supportive Care Team rounds at that institution.

Finally, it is important to review any cultural or spiritual rituals that need to be followed after the baby has died. Based on the mother’s (parents’) beliefs, the plan for either burial or cremation will be documented in the advance care plan. Often mothers (parents) have never thought about what happens after their baby has died and will ask for guidance on what funeral home to use or what other families have done in similar situations. In addition, financial resources can be explored to assist in lessening one stressor from the mother (parents).

Advance care planning is essential for the perinatal population. Mothers (parents) need to know what to expect once their baby is born. Knowledge is a powerful tool for families who are grieving and need to plan for what may be a very brief time with their baby. A comprehensive advance care plan will include resuscitation status, plan for feeding, location of death, pain and symptom management recommendations, spiritual and religious requirements. If the mothers (parents) have asked for photography, music, or specific lighting, these requests are documented. Finally, the name of the funeral home can be included if known at the time of the initial meeting.

Advance care planning for expectant parents offers the opportunity for the parents to think about what they want and not want for their baby. In the past, the death of a baby was often not talked about and mothers (parents) thought they could not express their grief either before or after the death. Advance care planning also assists healthcare providers, who are often uncomfortable with the topic of end of life, with providing expert care to these patients. Advance care planning is a right for everyone, even babies.
VALUE-CENTERED CARE:
SUPPORTING FAMILY DECISION-MAKING WITH A NARRATIVE APPROACH

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Narrative medicine offers a framework to uncover the values that a family relies on to make decisions. This value-centered approach to care begins by hearing a patient or family's understanding of the clinical situation.

“We were told that Holly might not survive birth. We were prepared for her not to be breathing, and we chose ‘do not resuscitate’ unless she showed some effort to breathe. She came out crying, and here we are one day later. The team is asking us what we want to do next. They asked if we are okay with intubation now that she survived birth. They placed an NG tube to give her sugar and asked if we want to keep it in. We do not know what to do.”

Holly was born at term with multiple brain abnormalities of unknown etiology including significantly enlarged ventricles and an underdeveloped cerebellum. Her parents, Dan and Rachel, met with a Neonatologist and a Neurodevelopment Pediatrician prior to her birth. They were given a lot of medical information and prepared for the possibility that Holly may not survive. They had a clear plan around resuscitation at birth. If Holly showed respiratory effort, provide resuscitation. If not, focus on comfort care. At birth Holly was breathing spontaneously and required brief positive pressure ventilation. At 24 hours of life she was on minimal respiratory support, 1 Liter of oxygen, via a nasal cannula.

What remained was a lot of uncertainty and confusion. The team requested a palliative care consult to help understand the family’s goals of care.

“We need to know what Holly’s parents want us to do?” the team articulated to me during our discussion.

The team reviewed their discussion over the past day with Dan and Rachel. With each intervention the team looked to the parents to decide whether or not each specific action was appropriate. The team had no framework to guide their decision-making and so turned to the family for guidance on each medical decision.

“We are conditioned in medicine to think of many end-of-life decisions as choices that should be approached linearly. “Would you like us to resuscitate her if her heart stops?” “Are you okay with us placing a breathing tube if she cannot breath on her own?” “Is feeding via a feeding tube acceptable?” We act in algorithms, which have decision points that offer choices, and we naturally offer patients and families choices from this cognitive construct.

While this linear approach to code status and advanced care planning is often navigated by families, a line-item approach to decision-making can lead to increased family suffering from the burdens of weighing and making medical decisions. When a clinical situation offers more clinical certainty, asking a family their preference for some or all of these decisions may be appropriate. When nuance and uncertainty cloud the clinical course, training and experience have taught me a better way to elicit goals of care and offer support in decision-making.

“Can you tell me what your understanding is about the medical situation?” I asked Dan and Rachel at the beginning of my consult.
“We are really confused as to which direction things are heading. We know that Holly needs the oxygen to support her breathing and has required some glucose through the NG tube due to low sugars.”

“Can you tell me more about your confusion?” I continued.

Dan and Rachel expressed the uncertainty of the present situation and shared their primary concern of not wanting Holly to suffer. They also discussed the possible outcomes they heard from the teams, ranging from Holly not surviving birth to leading a life dependent on others for all of her activities of daily living.

Beginning a conversation by eliciting understanding of a situation offers the opportunity to hear in the family’s words the things they have taken away from the many conversations with medical teams. It focuses the conversation on the family, their experience, and their process. Often, when asking a family what they understand, their first response is one of expressing grief, hardship, confusion, or stress. This provides an opportunity to acknowledge the loss of a normal pregnancy, the stress of the situation, and the range of emotions that normally accompany life in times of chaos and uncertainty.

Open-ended questions addressing understanding often draw out concepts that require more investigation. In this case Dan and Rachel expressed their confusion over what direction Holly’s situation was moving. By continuing the conversation and asking them to share more about this confusion, I heard the important value of not wanting Holly to suffer.

“I hear that Holly’s suffering is a primary concern for you. Do you feel that she is suffering right now?”

“She doesn’t appear to be suffering now. What do you think?” her parents responded.

“T see a beautiful girl who appears very comfortable.”

At the heart of Dan and Rachel’s angst over these medical decisions was whether or not an intervention would cause Holly to suffer unnecessarily. Hearing the values that underpin quality of life for families can help the medical team further appreciate how to support families in decision-making.

“Are there other things that you are worried about?” I asked.

“We are worried about Holly leading an over-medicalized life,” they responded.

“Can you tell me more about what an over-medicalized life looks like to you?”

Dan and Rachel described their experience of caring for children with special needs. As teachers they have cared for students with special needs in their classrooms. They expressed that a life dependent on a ventilator did not make sense for Holly given all of her underlying problems.

“What things are you hoping for?” I asked.

“We hope that we can take Holly home, but mainly we want her to be comfortable.”

By asking about a family’s concerns and hopes, one can uncover values that provide a framework for supporting families in their decisions and when appropriate make recommendations. Rachel and Dan desired to avoid unnecessary suffering and an over-medicalized life for Holly. Additionally, they preferred to focus on her comfort but desired to have her home. These preferences when reviewed with the primary team and put into the context of Holly’s evolving clinical situation, offered a way to support Dan and Rachel as they navigated uncertainty.

“What is important for you as a family right now?” I asked.
“We want to hold Holly as much as we can and spend time as a family.”

We discussed specific ways that Dan and Rachel could spend quality time with Holly. The bedside nurse arranged to bring a hospital bed in the room so that the family could be together in bed. The social worker called to arrange pictures with Holly, Dan, and Rachel.

“If Holly faces the end of her life, what is most important to you as a family?” I continued.

“We would want to be by her side and allow her to die as peacefully as possible.”

“Given what you have told me, it sounds like CPR would not be the right thing for Holly,” I offered.

Dan and Rachel agreed. We discussed how intubation was more difficult to decide against at this time so for now a decision to intubate her if she needed it for a short time was in line with their goals. We reviewed the NG tube that Holly had in her nose. She was not bothered by it, and it was not causing her to suffer. I offered that if they sensed it was causing her to suffer then we could readress it at that time. If it came out, we could choose to not replace it.

Dan and Rachel’s family narrative emphasized focusing on comfort and spending time as a family. If Holly’s condition worsened and the end of her life approached, a focus on peace, calm, and the avoidance of chaos was a priority. Given these preferences, CPR did not seem to make sense for Holly. I was able to make this recommendation to them and sort through other decisions with them in a way that focused on their values.

We can best support families facing uncertainty by uncovering the values that inform their decisions. A narrative approach provides value-centered care by eliciting understanding, hopes, concerns, and other factors affecting quality of life such as what is most important to a family in the present moment and at the end of life if it approaches. This is a method that can be implemented by any care provider working with a family facing complex decision-making. Begin by assessing understanding and build upon that common ground.

Value centered care gives us an opportunity to acknowledge family decision-making on an emotional level and to make recommendations for care when appropriate. It can help to alleviate some of the burden parents face with decision-making and allow parents like Dan and Rachel to be more present with their daughter.

Over the next several days, Holly was weaned from her oxygen and prepared for a discharge home. I recommended home pediatric hospice care as it fit the values underlying Dan and Rachel’s goals of care for Holly. On the day of discharge, they were able to articulate the joy and grief they had experienced.

“We are so grateful to everyone here for supporting us in this difficult journey. We have felt every emotion these past few days, but we feel like we have been able to be Holly’s parents.”
IMPLEMENTING ADVANCE CARE PLANNING AND UTILIZING ADVANCE CARE PLANNING TOOLS

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Advance care planning is a process by which goals of care are clarified, preliminary decisions are made, and treatment plans are developed consistent with the values and preferences of the child/parents. Advance care planning focuses on living, no matter how long, and supports appropriate hopes. The process gives the child/parents a sense of control. It is an opportunity to ensure that the child, parents, and providers are “all on the same page.” A written advance care plan (ACP) documents the discussion and can be disseminated to all current and future care providers.

There are several advance care planning tools that are designed for and/or are used in the pediatric population, especially for children with life limiting diseases/conditions. The following are some of the tools:

- My Wishes (pediatric version of 5 Wishes)
- Wishes
- Voicing My Choices
- My Choices
- Respecting Choices/FACE (Family/Adolescent CEntered advance care planning)
- POLST (varies by state)
- Emergency Information Form for Children with Special Health Care Needs (American Academy of Pediatrics)

Components of the ideal ACP tool

The advance care planning process and the ACP tool/document are individualized according to the needs of the child/family.

- Clarity of goals: Goals of care are especially important in the face of prognostic uncertainty.
  Typical goals might include:
  - Improving duration of life
  - Improving quality of life
  - Minimizing pain and suffering
  - Optimizing health and function
  - Ability to be cared for at home

- Family information
  - Who is in the family? Don’t forget the siblings and grandparents.
  - Who are the decision makers? This is usually the parents or a parent, but it might be other family members, an elder or religious leader, or a legal guardian.

- Financial information
  - Insurance coverage
  - Any financial considerations

- Team information: there should be a team member available 24/7/365
  - All treatment providers with contact information and when to contact which provider
  - Key contact
  - Who should they call in a crisis?
    - EMS?
- Designated team member?
- Hospital's telephone nurse advisor?
  - Involved community agencies
- Current diseases/conditions
  - Prognosis and degree of certainty
  - Likely trajectory
  - Likely complications
  - Understanding by child/parents of the disease/condition
- Current treatments including benefits and burdens
  - Medications
  - Potential symptoms and recommended treatments
  - Technology support
  - Therapies such as PT/OT, speech, audiology, music, art, etc.
  - Plan for respite care if applicable
  - Triggers for seeking immediate attention
- School issues
- Emotional, psychosocial, cultural, and spiritual issues and management for child, siblings, and family
- Decision making/preferences
  - All treatments should meet the child's/parents' goals
  - Desired site of care, including site of death if applicable
  - Current resuscitation status (be specific)
  - Conditions under which treatment decisions might change, for instance
    - Circumstances where the child/parent might no longer want intensive life-prolonging treatment (including resuscitation) for high burden of disease/condition/treatment, inability to go home, or failure of treatment to improve duration or quality of life
    - Circumstances where the child/parent might wish intensive life-prolonging treatment such as low burden treatments for a reversible disease or condition
- If child is near death, the following issues should be addressed:
  - Making memories
  - Preferred site of care and death
  - Who will declare death
  - Who will contact coroner/medical examiner/health care providers
  - Autopsy
  - Organ donation
  - Burial/cremation
  - Funeral/memorial services
  - Bereavement follow up
- Participants in development of the ACP
- Date of ACP and updates
- Plan for dissemination of ACP and updates

Who should be involved in the ACP conversation? A trusted team member who is familiar with the child/family is the best person to introduce the process.

- Participants (as appropriate and available)
  - The child who has decisional capacity should be involved if he/she desires
  - The child’s legal guardian(s), usually the parents, and primary decision maker(s)
  - Support people identified by the child/parents
  - The lead physician, involved specialists, and primary care provider
  - Ancillary providers such as social worker, chaplain, OT/PT, child life specialist, etc.
- Conversation can be led by the physician, a team member, or by a facilitator, such as with the Respecting Choices model
- Some tools may be completed primarily by the child/family
When should there be an advance care planning conversation? I agree with Fraser who advocates “…that end-of-life planning should take place with children and their families at an opportune time following diagnosis, and not just prior to death.” Advance care planning should be integrated into routine care. It should be part of regular multidisciplinary team meetings with child/parents much as an IEP (Individualized Education Program) is developed for special needs children. Predicting time of death and difficulty of raising the issue should not be a barrier. There should be a conversation:

- During period of stability
- Soon after diagnosis of disease/condition
- If there is a change in trajectory of disease
- If the answer to any of the following questions is “no”
  - Would you be surprised if this child died within a year?
  - Would you be surprised if this child died during this episode of care?
  - Do you know what the child and parents’ wishes are for the end of life?

What might the process look like?

- The ACP might be documented and updated after regular multidisciplinary team meetings as noted above.
- The ACP might be completed after a ~1 ½ hour long, facilitated, structured conversation. (Respecting Choices)
- The ACP might be presented as modules and completed over time (Voicing My Choices)
- There should be opportunities for regular review and updating, especially with change in the trajectory of the disease/condition
- The utility of the tool is strengthened with signatures from the physician and the child/parents
- The tool should be always available, ideally with the child. It might go with all car seats, on the refrigerator, at school, at the local emergency room, in the clinic and hospital medical records, etc.
- After the tool is completed and with consent of the child/parents, the written tool is disseminated to all current and potential care providers. If there were a central repository, there would be wide access by providers, parents, specialists, and emergency staff. In absence of that, the ACP should be included in the electronic or written medical record and mailed to other providers to include in their records.
- Whenever the child is in the clinic, ER, or hospital, the child/parents should be asked if their treatment preferences remain the same or if there are any changes. If there are changes, the ACP should be updated and the new document disseminated.

Questions to ask about the tool:

- For which population is this intended?
  - Children with decisional capacity
  - Adolescents/young adults
  - Parents of children without decisional capacity
- Where is the tool applicable?
  - In-patient
  - Outpatient (POLST, Emergency Information Form for Special Needs Children)
  - Will the school honor the ACP?
  - Will EMS staff honor the ACP? If so, will they provide an alternative phone number to call to arrange transport to the hospital if requested?
- Is this tool legally binding?
  - Most tools are not legally binding in minors
  - In some states, POLST is legally binding for minors

Advance care planning is a process applicable to all children with potentially life-limiting
The written ACP is a useful tool to document preferences and facilitates coordinated and consistent care from different providers and at different sites. However, obtaining the document is only possible if there is a conversation. The conversation is particularly important with prognostic uncertainly and should not wait until shortly before death.

**Resources**

12. Liberman DB, Pham PK, Nager AL. Pediatric advance directives: Parents' knowledge, experience, and preferences. Pediatrics 2014;134;e436
13. Lotz JD. Jox RJ, Borasio GD, Fuhrer M. Pediatric advance care planning: A systematic review. Pediatrics 2013;131;e873
examples of goals of children with medical complexity.


27. Walter JK, Rosenberg AR, Feudtner C. Tackling taboo topics: How to have effective advanced care planning discussions with adolescents and young adults with cancer. JAMA Pediatr. 2013;167(5):489-490


COURAGEOUS CONVERSATIONS: IMPLEMENTING ADVANCE CARE PLANNING WITH ADOLESCENTS AND YOUNG ADULTS

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Quality care for adolescents and young adults depends on access to health care professionals who possess knowledge specific to the unique psychosocial context for the biomedical and psychosocial needs of this population, including the assessment of and attention to cognitive, psychiatric, and psychosocial issues throughout the trajectory of illness.¹

Developmental characteristics of the adolescent and young adult (AYA) population are especially important to consider in the context of end-of-life (EoL) care decisions. AYAs are often in the process of developing autonomy from their family of origin. This increased independence includes greater responsibility for personal decisions, including about healthcare. Evidence suggests that adolescents with cancer are able to make competent healthcare decisions and want to be involved in medical decision-making²,³ including regarding EoL care.⁴,⁵ Lyon and colleagues found adolescents felt empowered when communicating their EoL care preferences during family centered advance care planning interventions.⁶ However, these decisions are new for many AYAs who often have limited experience with illness and the healthcare system.⁷ Therefore, providing supportive resources that respect AYAs’ autonomy are important for effective EoL care planning in this population.

Advance care planning (ACP) documents and advance directives provide patients with the opportunity to express their preferences for care. These directives can help families and health care agents make informed decisions, alleviate distress, avoid decisional regret, and potentially improve the patient’s quality of life by respecting their religious, cultural, and familial values and beliefs.⁸,⁹ However, few resources exist to aid AYAs in addressing their changing physical, emotional, and social needs and wishes around
EoL. In addition, research in pediatric oncology indicates that, even when ACP does occur, it is rarely documented which significantly limits the potential benefit.\textsuperscript{10}

In response to the lack of developmentally targeted resources for ACP in AYAs, researchers at the National Cancer Institute’s Pediatric Oncology Branch examined whether Five Wishes, a widely used advance directive, is relevant for AYAs. At the time, Five Wishes was the only advance care planning guide that included issues of comfort, future planning, and spirituality along with choosing a durable power of attorney and specific life support options. AYAs age 16-28 years reviewed Five Wishes and commented on its relevance for the AYA population. Most participants reported that an advance directive like Five Wishes would be “helpful” or “very helpful” to them (95%) and to others (90%).\textsuperscript{11} In addition, participants identified items concerning how they wanted to be treated and remembered as more important than items concerning specific medical decision-making.

Using the feedback and recommendations obtained, the study team designed an AYA-specific advance care planning guide, My Thoughts, My Wishes, My Voice (MTMWVM) which 52 additional participants age 16-28 years living with HIV or advanced cancer compared with Five Wishes.\textsuperscript{12} During this phase of the study, participants identified items they wanted added and/or omitted and made suggestions for formatting of content. This feedback was utilized to develop the final document, Voicing My CHOICES™ (http://www.agingwithdignity.org/vmc). Several changes were made from MTMWVM to Voicing My CHOICES™. First, the document was renamed to reflect participants’ opinion that as EoL nears, both their choices and their voice need to be heard. Voicing My CHOICES™ allows AYAs to reflect on their life and to make choices about what nurtures, protects, and affirms their remaining life and how they wish to be remembered into the future. Additionally, the same prioritization repeated itself with the new revision, i.e., rating how they want to be treated and remembered as more important than specific medical decision-making. As a result, issues related to comfort, spirituality, and relationships are emphasized in Voicing My CHOICES™. Second, AYAs also recommended use of developmentally appropriate language (e.g., “It is important that my family get along”), clarification of medical concepts, and the inclusion of friends in several sections. Finally, AYAs expressed a preference for both closed (yes/ no) questions and open-ended questions and provided suggestions for document design, color, and simplified wording.

While the availability of AYA specific advance care planning guides is beneficial, successful use of them relies profoundly on whether they are actually integrated into adolescent care. It is highly recommended that Voicing My CHOICES™ be completed with the assistance of a health care provider. Familiarity and training is necessary for providers who may utilize the document in their practice, including physicians, nurses, social workers and psychiatrists/psychologists. Suggested guidelines and ‘scripts’ on how to introduce Voicing My CHOICES™ and EoL planning into the practice setting, critical time points at which a patient’s goals of care should be re-introduced and discussed, and ways to empower the patient and incorporate the family in EoL planning have been recently published by the study team.\textsuperscript{13, 14} Sample statements to introduce Voicing My CHOICES™ are provided. For example,”Although we are hoping that this next treatment (medicine) will be helpful, many people your age have told us that they found it helpful to have a say about what they would want or not want if treatment doesn’t go as expected. In fact, people your age helped create a guide so that they could put down on paper things that are important to them.” Suggestions on how to work through each section alongside the patient are also provided.

Involving the health care provider in completion of advance care planning can provide an opportunity to establish rapport and to gently introduce EoL and elicit preferences. Moreover, this relationship may facilitate an easier transition moving into the more serious modules and in revisiting preferences as the treatment trajectory changes. An online survey was sent to providers who requested Voicing My CHOICES™ several months after it became available. Providers were asked, “Did Voicing My CHOICES™ meet your expectations?”, “Do you intend to use Voicing My CHOICES™ in the future?”, and “How might we improve Voicing My CHOICES™?” One hundred percent of respondents reported that the document met their expectations, 85% intended to use the document in the future, and requests were made for the document to be translated into different languages (it is now available in Spanish). Providers were also asked to, “Share your impression of Voicing My CHOICES™ and how you’ve used it.” The comments primarily addressed how the document has been an excellent communication tool. Yet,
whether completing sections of *Voicing My CHOICES™* results in reduced anxiety, improved perceived emotional support, and enhanced communication about advance care planning with family and/or health care providers in AYAs is not yet known. A multi-institutional study has recently opened which will help provide insight into these critical questions.

There has been very promising and exciting research by Lyon and colleagues that has found acceptability and efficacy of an ACP intervention with adolescents with cancer and their families using the Family CEntered Advance Care Planning for Teens with Cancer and HIV (FACE) model As part of a randomized controlled trial, Lyon and colleagues customized *Respecting Choices*® [http://www.gundersenhealth.org/respecting-choices](http://www.gundersenhealth.org/respecting-choices) for adolescents with cancer and HIV. All participants were given a brochure with information on ACP but only the intervention dyads received a 3-session, facilitated conversation that included: (1) the Lyon Family-Centered ACP Survey (which assesses the adolescents’ and surrogates’ values, beliefs, and life experiences with illness and end-of-life care); (2) the adapted *Respecting Choices® Next Steps ACP* interview; and (3) completing *Five Wishes*. During the *Respecting Choices® Next Steps ACP* interview, facilitators elicited the adolescent’s and surrogate’s understanding of the current medical condition, prognosis and potential complications, fears, hopes, and experiences; explored the adolescent’s understanding of ACP; reviewed the rationale for future medical decisions; used the statement of treatment preferences to encourage dialogue about goals and values in real “bad outcome” situations; promoted understanding of the adolescent’s goals and values with the surrogate; and addressed the need for future discussions as situations and preferences change. The adolescent’s responses were documented on a written plan to be entered into the medical record to guide future medical decision making as appropriate.

Findings revealed that those in the intervention group were empowered during the FACE-TC and FACE-HIV ACP intervention to communicate their wishes for their own EoL care to their families. An environment was created in which families could listen to their adolescents discuss fears, hopes, and preferences, which in some situations included discontinuing unnecessary or unwanted care. The three-session FACE model increased documented ACP; implementation comfort increased congruence in treatment preferences between adolescent patients and their families, and reduced anxiety. Importantly, families verbalized a commitment to honor these requests.

The comparative effectiveness of completing *Voicing My CHOICES™* with a health care provider or on one’s own; or completing the three-session FACE ACP intervention with a trained/certified facilitator using *Voicing My CHOICES™* versus *Five Wishes* is not known. Future research will guide us. Implementation research should be conducted to demonstrate the effectiveness of these models for minimizing suffering and enhancing quality of life for the adolescent with cancer, their family, and the treatment team in pediatric hospital-based systems. The most important goal is for pediatric ACP models to be incorporated as standard of care. As we move forward, measuring documentation of ACP in the electronic medical record will be an essential quality service indicator.

**References**


Acknowledgement: This research was supported [in part] by the National Cancer Institute Intramural Research Program of the NIH
The topic of advance care planning for children with medical complexity (CMC) would be incomplete without some thought for implementation in the school setting. While it is very rare that children die while in school, for CMC who are able to and desire to attend school, it is important that goals of care are clarified. This is fraught with complexity, as noted in this policy statement by the AAP. In this open access article, you will find a review of available data on DNR policies in the school setting, general lack of supporting local and state regulation, and suggestions for an action plan that should accompany any advance care plan including withholding non-beneficial resuscitation. Following the presented guidelines proposed by the AAP should facilitate complying with the child/family’s preferences while minimizing the negative impact on school systems, school staff, and other children in attendance. I have also included a link to an ethics commentary and a reference to a review of pertinent policies and laws.


ITEMS OF INTEREST:
In each issue of our ChiPPS E-Journal, we offer additional items of interest.

1. SUBJECTS AND CONTRIBUTORS FOR FUTURE ISSUES OF THIS E-JOURNAL. For upcoming E-Journal issues, we plan to address topics related to: a starter kit or "how to" tools for new programs in pediatric palliative/hospice care; another look at concurrent care; and respite care. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at christytork@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

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

3. NINR FAMILY SURVEY SAMPLE SOCIAL MEDIA CONTENT palliative care: CONVERSATIONS MATTER® The National Institute of Nursing Research, part of the National Institutes of Health, has created a survey to gather feedback from parents and families of children with serious illnesses. This campaign survey will inform upcoming efforts to provide families with information and resources they deem valuable. NINR hopes to learn what might be helpful in supporting their journeys—and those of many other families who have, or will, experience similar situations when caring for children with serious illnesses. To this end, NINR invites families to share their thoughts through a brief 10-question survey. The questions are short, and the survey should take 10 minutes or less to complete. All responses are anonymous and no personal information is collected. The survey will remain open through Friday, February 20. https://www.surveymonkey.com/s/VKFHYP7.

4. WOULD YOU LIKE TO JOIN THE CONVERSATION WITH OTHER PEDIATRIC PROFESSIONALS? Join American Academy of Pediatric’s LISTSERV® e-mail list! The List is open to anyone with an interest in pediatric palliative care and hospice medicine! Visit the AAP Section on Hospice and Palliative Medicine web page at http://www2.aap.org/sections/palliative/listsub_unsub.html and enter your email address to receive/send messages and click the subscribe button.

5. NEW PEDIATRIC PAIN, PALLIATIVE AND INTEGRATIVE MEDICINE CLINIC OPENS AT CHILDREN’S HOSPITALS AND CLINICS OF MINNESOTA. This innovative clinic is designed as a state of the art “healing environment” to enhance the well-being and alleviate the stress and suffering of patients and their families. This healing environment also supports the clinicians in their efforts to promote physical, emotional and spiritual healing. This environment is varied throughout the space to appeal to different age groups and to support specific treatments including not only traditional medical therapies but also biofeedback, group therapy, physical therapy, massage, aroma therapy and acupuncture. To learn more, read http://mspmag.com/Out-And-About/Articles/Features/Horst-Rechelbacher-s-Legacy/.

6. NEW SYMPTOM MANAGEMENT RESOURCE AVAILABLE. Pediatric Palliative Care Consultant is a guide is to equip all practitioners who care for pediatric patients with chronic life-limiting conditions, whether they have pediatric-specific training, or rarely see a pediatric patient. This reference provides relevant background information regarding symptoms, as well as non-pharmacological and pharmacological treatment options. To order, visit www.hospibooks.com and use the discount code CYGB6D9Z to receive 25% off.

7. PEDIATRIC CONVERSATION STARTER KIT AVAILABLE. A new resource created by The Conversation Project for parents of critically ill children, Pediatric Starter Kit: Having the Conversation with Your Seriously Ill Child, is available for free download. The Kit offers advice and provides stories from parents and palliative care specialists who have been there, and offers questions that can help parents navigate the approach to the conversation based on the personality and cognitive level of the child.
8. “VISION OF HOPE” CURRICULUM INTEGRATES PALLIATIVE CARE IN CHRONIC PEDIATRIC DISEASE. Scholars from the Johns Hopkins Berman Institute of Bioethics launched a new curriculum for training diverse healthcare workers to apply palliative care principles to pediatric patients suffering from sickle cell disease and Duchenne muscular dystrophy. The curriculum guides healthcare workers in integrating the principles and practices of pediatric palliative care into their long-term care regimen. The “Vision of Hope” curriculum uses two specific chronic conditions as case studies: sickle cell disease and Duchenne muscular dystrophy. All content is free and publicly available at http://www.bioethicsinstitute.org/hope.

9. JORDAN’S JOURNEY INSPIRES MOMENTS OF LIFE. Jordan’s Journey provides an inspirational account of how hospice helped a family. Read Jordan’s Journey and view other stories on NHPCO’s national awareness campaign Moments of Life: Made Possible by Hospice.

10. PEDIATRIC PALLIATIVE CARE CONFERENCES, TRAININGS AND MEETINGS:
   - Become an EPEC-Pediatrics Trainer: The next EPEC-Pediatrics conference will be held on May 4-5, 2015 in Phoenix, AZ in conjunction with the American Society of Pediatric Hematology/Oncology annual meeting. The course is primarily designed for physicians and nurse-practitioners taking care of children, but will eventually be open to other clinicians and psycho-social-spiritual staff providing pediatric palliative care. To register, visit http://www.cvent.com/d/q4qy0y. Learn more about the EPEC-Pediatrics modules at http://epec.net/documents/EPEC-PEDs_CurriculumListing_Objectives.pdf.
   - The American Society of Pediatric Hematology/Oncology 28th Annual Meeting will be held May 6-9, 2015 in Phoenix, AZ. To register, visit http://aspho.org/meetings/annual-meeting/2015/registration.
   - Pediatric Pain Master Class will be held June 20-16, 2015, in Minneapolis, MN. The Pediatric Pain Master Class offers state of the art education in pain management for the pediatric patient from a holistic and interdisciplinary perspective. The program features a faculty of internationally recognized experts who will cover pharmacological, medical, psychosocial and integrative aspects of pediatric pain management. Learn more and register here.
   - 7th Cardiff International Conference on Pediatric Palliative Care is planned for July 8-10, 2015, in Cardiff, Wales, UK. The conference, “Medicine and Compassion: Tool for the Task…Or Dangerous Distraction?” is sponsored by the International Children’s Palliative Care Network and by Cardiff University. More information is available at www.icpcn.org.
   - NHPCO’s Pediatric Palliative Care Training and Intensive. Held in conjunction with NHPCO’s 15th Clinical Team Conference in Grapevine, TX, the two-day Pediatric Palliative Care Training will be held Oct. 13-14, 2015. This two-day preconference seminar will provide pediatric palliative care training for new and developing pediatric palliative and hospice care professionals. The Pediatric Intensive held during the Clinical Team Conference, Oct. 15-17, is an intermediate level session track designed to develop professionals and organizations to provide care to infants and children facing life threatening conditions and their families. Visit NHPCO’s education webpage for more information and registration details.

11. CALENDAR OF EVENTS. As a reminder, pediatric educational opportunities are available on www.nhpco.org/pediatrics. Please e-mail Christy Torkildson at christytork@gmail.com to have your pediatric palliative care educational offering listed in the ChiPPS E-Journal.
Please note that the opinions expressed by the contributors to this issue are their own and do not
necessarily reflect the views of the editors of this newsletter, ChiPPS and its E-Journal Work Group, or
NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible
publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing
pediatric palliative and hospice care to children, adolescents, and their family members has made great
strides in recent years, even though it is certainly not always easy and still faces many challenges and
obstacles. We wish you all the best in your good work.

If you are not on our mailing list and received this newsletter from a friend or some other source, please
send an email message to pediatrics@nhpco.org requesting to be added to our mailing list. If you are a
member of NHPCO, you can go to the Communications Preferences tab in your individual member
record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you
adjust your communications preferences; contact them at 800-646-6460. Visit the NHPCO/ChiPPS Web
page at www.nhpco.org/pediatrics for further materials and resources of interest.

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