



E - NEWS

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Issue Topic: Families Experiencing Transitions

Welcome to the fifteenth issue of the ChiPPS electronic newsletter. This issue of our e-newsletter addresses issues associated with families experiencing transitions in pediatric palliative care. The articles in this issue describe experiences of family members when they do not feel prepared for whatever they are facing and what can be done to prepare such families for things they might encounter. Below you will find links to a PDF collection of articles on these topics that were contributed by family members and professional colleagues.

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 Communications Work Group, co-chaired by Christy Torkildson and Mary Kay Tyler. Comments about the activities of ChiPPS, its Communications Work Group, 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 torkc@sbcglobal.net.

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Issue #15: Preparing Families for Transitions in Pediatric Palliative Care

(Click on the "bookmark" tab on the left-hand side of the PDF document for links to the following articles.)

Alone, Unprepared, But Not Hopeless

p. 4

Myriam Avery

With honesty and courage, Julian's mom shares the challenges of caring for her son at home. We thank her for her courage and hope it will help us help others.

No Time to Get Prepared Before He Was Gone

p. 6

Ruth Ruley

With raw emotion and courage, Angel's mom shares her grief and difficulty with her son's final transition. There is no better introduction than her own words:

"After multiple attempts to write this for you, this is what I've managed to come up with. It may not be what you're looking for, but it's the best I can do; I bawl whenever I think about the whole thing, and I so badly want to help you with this, but I also have to be able to survive without my son..."

Hope is the Thing: Communicating With Families in the Continuum of Hope

p. 7

Maureen Horgan, LICSW

Maureen builds on her earlier work to provide us with a thoughtful and practical article that describes why joining in hope builds trust. The article also provides practical approaches to dialogue that promote hope while introducing palliative care concepts and eliciting goals of care.

Silent Companion

p. 13

Stephanie Harris Miller, MTS

'When words are not sufficient to express all that is in the heart, another connection takes place.'

Using case examples, Stephanie shares with us the power of silence and as she writes "...walking with someone in silence...has the power to create trust in ways we cannot imagine."

Connections: Chaplains, Palliative Care, Patients, and Their Families

p. 15

Rev. George B. Lambrides

Rev. Lambrides explores connections and the role of the chaplain in pediatric palliative care. With the use of case studies he explores the connections that staff and family members may make, from the practical to the spiritual. He answers the question of "what is it we have to offer?" for our families facing many transitions from diagnosis through bereavement.

Transition From Hospital to Home Hospice Care: A Case Study

p. 18

Constance Bergh, MSH, RN, and Kelly Cronin Komatz, MD

From birthing plan through bereavement, Constance and Dr. Komatz provide an excellent case study to facilitate discussion for you and your teams

Leaving the Hospital: Roadways, Road Bumps, and Detours

p. 20

Margaret Farrar-Laco, RN, MSN, CPNP, Stephanie Allen, RN, and Sarah Friebert, MD

The authors provide useful guidelines to help providers and families navigate the 'roadways, bumps and detours' so many of our families must travel. As stated by the authors, "there are many options available..." and having a roadmap makes the trip much more bearable for all involved. The authors include forms that may be modified for your own setting in the appendix.



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A Sibling's Grief: Considerations to Best Support a Child Facing Loss

p. 30

Beverly Goldsmith, MSW, and Stacey Jones, MSW, LASW

By increasing our own understanding about how children experience grief and loss, we can better assist children through the normal and necessary process of grieving. This article addresses the significance of an illness or death in a child's life and the grief reactions that may occur. It also emphasizes helpful considerations when a child's sibling is seriously ill or has died. Finally, the article includes tools and verbiage which can assist both professionals and adult caregivers to best support children facing such difficult situations in their lives.

An additional article of interest provided to readers:

NHPCO's Pediatric Standards: A Key Step in Advancing Care for America's Children

p. 36

Sarah Friebert, MD, and Susan Huff, RN, MSN

In partnership with ChiPPS, NHPCO has developed its first national Standards of Practice for Pediatric Hospice and Palliative Care Programs to help providers develop safe, effective and high-quality programming for children and their families. This article originally appeared in NHPCO's *NewsLine*, February 2009.

Items of Interest

p. 39

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

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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.



ALONE, UNPREPARED, BUT NOT HOPELESS

Myriam Avery
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Julian was 2 months shy of 4 when he was diagnosed with a malignant brain tumor called medulloblastoma. Of course that was a big shocker, BUT we knew so little about everything that we just went with the flow. After a successful surgery (total removal) and a clean spinal tap, they gave us 75-80% chance of a cure. We took it and ran. Julian was going to make it; the odds were in his favor. Julian went thru most treatments just fine. Our main issue was taking meds orally and eating. After the initial surgery and having to take Tylenol and Motrin around the clock and throwing them up around the clock, he was DONE with oral meds! Which in itself was bad because to keep him from getting PC pneumonia he had to take antibiotics Monday thru Wednesday every week. It just didn't seem at that point we got much help or tips to make him take his meds. We got some relief in the form of a dreaded NG tube. We could then dispense the meds that way. And eventually got a G-button which was amazing. So, where we need more help after diagnosis is in the care department. You are thrown in this world with NO practice in caring for a very ill child. They give you your prescriptions; send you home and good luck!

Now, our big shock was when we found out that Julian had relapsed only 6 months into treatment. NOTHING prepared us for that. It was in the back of our minds; we knew medullo kids relapsed regularly, but usually off treatment. We weren't prepared at all. We felt so betrayed, but not sure by who or what, just let down in a big way and dealing with it on our own. This just doesn't happen; our oncologist told us he had never seen this. At that point, one of the three options he gave us was to sign up with hospice and take Julian home with no further treatment. We couldn't believe it was already an option! The doctor was present, along with the social worker and a nurse. Of course we opted for more treatment at that point; we just had to pick between a couple of alternatives. Again, you are faced with those decisions alone. Our doctor was supportive of whatever we wanted to do, but we had to do our research first to see if there was something out there he didn't know about.

Julian's relapse was very aggressive and whatever we tried just didn't work, cancer invaded his brain and spine in a big way. Just a month after relapse was confirmed, we made contact with hospice, signed papers, including a DNR on our 4 year old... It seemed so unreal and yet we had to do this alone. After the initial pain of having to do this, we worked very well with hospice. By then taking care of Julian and his meds didn't bother me anymore. But watching him decline was scary. They responded very well to our needs and sent nurses when we needed them. We had 24-hour care off and on which was a big relief, but we were always worried to see them leave as we knew Julian could leave us anytime. Julian passed away fighting for every breath. I read so many stories of children's last moments, trying to figure out what it would be like. Most said the same thing: they go in their sleep peacefully. So again, I wasn't expecting this and it was the most horrific experience... Watching him gasp for air like a fish out of water is haunting and I had no idea this could happen... I tried to find somewhere online that would guide us thru the end of life, but never found anything.

My big dream for each family whose child is diagnosed with cancer or any other life threatening disease is to have a support team from the day of diagnosis and who follows the family until they are not needed anymore, whatever the outcome is; a team built with different members for each need. I believe some hospitals are working towards that, ours is. But it isn't fast enough.

Families need to make ties with the team. They need to be able to call them when they have a scary scan coming up and have someone at their side when they get told both good and bad news. Some divorced or widowed parents go thru this alone. The team needs to know answers to questions such as "how will it be when my child dies?" And although all kids are different, telling the families different things they might expect would be extremely helpful. Even just questions like "how will my child wake up from surgery?"



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Families need more support, mentally (during tough times, during decision making, dealing with stress, depression) and physically (to learn to take care of their sick child, to have someone there with them for appointments if needed). The team should include nurses, doctors on call, social workers, counselors, and volunteers such as other cancer parents willing to be there for parents to talk to thru their journey.

After losing Julian and being helped thru the transition by a mom who had lost her baby to a brain tumor 6 months prior to Julian's death, I knew that I wanted to do that for other moms. I have made myself available to moms of children who have no more options. They know they can ask any question, tell me anything from how they feel to how their child is doing, they ask for advice. I share openly our experience and try to help them in ways nurses might not think of, such as make sure they take hand prints by paint or plaster, take lots of pictures and movies, or use one kind of lotion so when the child is gone they still have a scent to soothe them. These things are gifts that I treasure everyday but also things parents might not think of in those moments.

The hardest part is reaching out in a way they feel like they can talk to you. Maybe as I said, if parents volunteered as part of a team, whether with hospice or with a palliative care organization, it would be easier for them to find us and let us help...

I know I wish we would have had that from the day Julian was diagnosed and on during his journey...

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NO TIME TO GET PREPARED BEFORE HE WAS GONE

Ruth Ruley
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After multiple attempts to write this for you, this is what I've managed to come up with. It may not be what you're looking for, but it's the best I can do; I bawl whenever I think about the whole thing, and I so badly want to help you with this, but I also have to be able to survive without my son....

Along the childhood cancer journey there are many transitions to be made. Most of them are relatively simple; you alter your life. Pull your child out of school; add a med—or six; move into the hospital for treatment; or go home. Simple readjustment transitions.

Then there is that time when you get told there is nothing more... Nothing the doctors can do, and you have to transition from full out war on cancer to "Please God, don't do this."

With our son that final transition was so unexpected and so out of the blue we had no time to adjust. One day he was fine and the outlook to Christmas with no fissure was before us. The next week he was in the hospital for infection and no counts. The week after that we're told his bone marrow is 100% cancer and there's nothing we can do—our son will be gone by Christmas! We had to move from a future to hospice for our 8 year old.

How, as a parent do you do that? Who do you turn to for guidance? We had no idea what we were doing, no idea how to make the transition and no time to get used to the idea before it was over.

Two weeks and two days later he was gone and we had to make another transition—without him. How do we go from where we were to where we are? No clue.

I was asked to write about things I wish I'd known that would've helped make this easier.

There isn't anything that would've made it easier or any better—the worst hell in the world is to watch your child die and know there's absolutely nothing you can do. To have to tell him was so tough I was physically sick to my stomach and someone else had to do it, while I just held him and he asked why.

A child's death is so tough to deal with that there aren't many people to help you. You can't prepare because it isn't supposed to happen—you aren't suppose to outlive your children. Who do you turn to? How do you cope? I wish I knew.

No one out there understands what it's like to lose a child to something like cancer—no one other than other parents who have lost one. And even they can't help you prepare to go on without your child in your life.

The one thing I can say that would have helped is if people hadn't disappeared after his death. When we needed people around, they were gone. Even now, 2 years, 3 months and 22 days later, his loss still punches me in the gut and I can't function. There was no time to get used to "he's going to die" before he was gone.

I know that writing more would have been better, but this is the best I can do. It still hurts to think about losing him and to go over what it was like those last two weeks. And it is very true that no one can help you prepare for the death of your child; no one understands the depth of a loss like that other than parents who have lost their own child; and even they don't know what you feel...everyone feels it differently. I hope this helps—at least a little. I'm sorry it took me so long to get it to you and that it required nudging.

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HOPE IS THE THING: COMMUNICATING WITH FAMILIES IN THE CONTINUUM OF HOPE

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Children with life-threatening conditions and their families hold hope as a guiding principle in their decision making and daily living. Hope sustains. Palliative care and hospice teams are called to hold this hope and walk with families as they face changes amidst their hope. This article describes why joining in hope builds trust. The article also provides practical approaches to dialogue that promote hope while introducing palliative care concepts and eliciting goals of care. Pediatric program information in the article is gleaned from various national programs, and suggested standards of practice in pediatric palliative care. (This article is adapted from a presentation by Maureen Horgan and Jane Fleming of the Stepping Stones Program, given at the CHI Conference in November, 2008.)

The trick is, “just tell us the truth about what you think is going to happen, give it your best shot, and then let go...” These words of wisdom and profound knowing come from a bereaved mother who faced the devastating news of a cancer diagnosis, relapse, and the eventual death of her teenage daughter. She went on to say in her bereavement, “Are you afraid you will destroy our hope? We create our own hope. You are not a limiting factor in our sustaining hope.” The clinical “trick” that this mother and so many other families desire medical practitioners to perform is being present with compassion while disclosing prognosis and all treatment options including palliative care options. Talking about prognosis and palliative treatment options does not steal hope from patients and parents; in fact, it seems that it just isn’t possible to take away their hope. The prospect of relinquishing the hope for a cure and focusing exclusively on the final phase of life is simply too difficult for most families. Hope is a part of the package that comes with every family we encounter. It is the responsibility of every palliative care team member to meet families in that hope to assure best care.

To define hope is challenging and beyond the bounds of this article, but a general framework is acknowledgement that hope is extremely personal, is culturally expressed, and varies from person to person even within the same family system. The spiral is an image that may be helpful in describing the continuum of hope the families we support traverse in their journey and the support they need along the way. The spiral is an ancient symbol represented in art throughout the ages and across cultures. The spiral represents a path, yet where it begins and where it ends is unclear. The hope that families carry and embrace has new beginnings and endings throughout the experience of the child’s illness, from time of diagnosis into remission and/or bereavement. Wherever a family is on the spiral’s path they deserve to be surrounded and accompanied – there will always be a ring of the spiral juxtaposed to another ring. This image highlights that wherever patients, parents, and family and friends may be in their experience of hope, they never need be alone in the journey and that hope need never end.

Joining with a family in their hope is an essential initial step for palliative care providers and a natural extension of the palliative care approach which focuses on preventing and relieving suffering and supporting the best possible quality of life. Hope is “part of the package” that comes in some shape or form for each member of a family with a child with a life threatening illness. Moments of hopelessness occur in families across illness and into bereavement, and it is essential to use sound clinical assessment in those situations. Often they are moments; they are not the general undercurrent or overriding experience of the family. Families are moving and working to survive and the undercurrent of that survival is hope. From initial point of contact if we as professionals can embrace the concept of joining in hope, we build trust and rapport. As family hope changes and morphs across the continuum we can move and support them in the changes. Remember, the trick is, “We create our own hope. You are not a limiting factor in our sustaining hope.”



If we, the palliative care team, are not limiting factors in sustaining hope we can be champions with families in their hope and build trusting relationships grounded in compassionate listening and honest sharing of difficult information. Research supports the notion that truth telling and compassionate listening builds rapport and supports hope. "Hope and Prognostic Disclosure," a study by Mack and colleagues (2007), found no evidence that prognostic disclosure makes parents less hopeful. The study found that disclosure of prognosis by the physician can support hope even when the prognosis is unclear. Parents want accurate, clear, and timely information even if clinicians state that the situation is uncertain (Field & Behrman, 2003). Realistic perceptions of prognosis have the potential to transform hope – perhaps into a meaningful end-of-life period for the child and family.

Clinical Practice Strategies – Communicating Hope with Words

Various strategies exist for palliative care clinicians when supporting families in their hope. The initial meeting is an essential time to lay a foundation that clearly identifies a joining in hope. Given that some families learn about palliative services from their primary provider or primary specialist, a helpful approach is careful consideration of the name of your pediatric palliative care program. Families often become hesitant when learning that a palliative care clinician will be introduced and exponentially more hesitant when the notion of hospice is discussed. Feedback from families has shown that family and child-friendly program names that do not focus upon hospice or potentially even use the words hospice or palliative care are supportive to the family and may even increase their likelihood of meeting with the palliative care team. It is not uncommon at a first meeting for a parent to apologetically state, "We are hoping for a miracle." This statement is an opportunity to join in that hope and promote that hope with a statement such as, "As you think about your child's illness, can you tell me more about what you are hoping for? I would like to hope right along with you." If the child is present, an inquiry such as, "what are you hoping/wishing for" invites them into the conversation and instills the foundation that your primary focus is on their identified goals. Another effective approach is sharing at initial contact that at any time the family can decline palliative care services and perhaps even "graduate" from service. A bereaved mother stated, "It was so helpful that you said we could graduate from hospice. At the time I really thought it might happen and that we wouldn't need you, and then we did need you and were grateful to have you as part of our care team."

Eliciting and establishing goals of care is essential throughout the course of palliative care treatment. Meyer and colleagues (2006) in an article on "Improving the quality of end-of-life care in the pediatric intensive care unit" share specific recommendations that invite conversation, introduce the possibility of death, elicit goals of care, and talk about what families might expect. An essential consideration in incorporating these inquiries into your work with families is to assess what level of trust and rapport you have built, and where the family exists in the continuum of hope.

Inquiries that illicit information, build trust and build upon hope include:

- "As you think about your child's illness, what are your hopes?"
- "As you think about your child's illness, what are your worries?"
- "As you think about your child's illness, what is most important to you right now?"
- "I know you are hoping that the disease will be cured and I am hoping for that too. But I would also like to know more about your hopes and goals if a time comes when a cure is not possible."
- "You mentioned that what is most important to know is that your child be cured of her disease. I am hoping for that too. But I would also like to know more about your hopes and goals for your child's care if the time comes when cure is not possible."



- “Would it be helpful to talk about what to expect as your child’s illness gets worse? Although we cannot predict exactly what will happen, most children with this illness eventually have _____ (ex. difficulty breathing). If that happens our goal will be to help him feels as comfortable as possible. We can use _____ to help control his discomfort.”

Tulsky’s (2005) article, “Beyond advance directives: The importance of communication skills at the end of life,” also offers some helpful inquiries that promote and communicate hope and establish goals of care specific to end of life planning.

- “Have you thought about what might happen if things don’t go as you wish? Sometimes having a plan that prepares you for the worst makes it easier to focus on what you hope for most.”
- “You’ve told me you are hoping for a cure. Are there other things that you want to focus on as well?”
- “I wish too that this disease would stay in remission. If we cannot make that happen, what other shorter-term goals might we work toward?”

Clinical Practice Strategies – Self Awareness

The provision of palliative care and the process of holding hope with families is an art form that involves attentive communication, patience, the investment of time, and a great deal of practice. Attention to the words we choose is an essential element of this art form with families, with the teams we collaborate with, and within our own team context. Several approaches have been discussed related to word choice. Our clinical approach with families is so much more than the words we choose. Incorporating the following practice strategies may also support the goal of joining with families where they are on the continuum of hope.

Practice non-judgment. A simplistic starting point is refraining from using the term “denial” in any context related to the pediatric families we serve. As we work to assist families in re-framing their hope we can also benefit from re-framing the notion of “denial” into the notion of “extreme hope.” Given the phenomenal nature of grief and complex nature of death in the pediatric population, the concept of denial does not build a framework of support and collaboration that is essential for excellence in care. Parents and the entire community surrounding a child need to know they did everything they could to care for and assist their child in living. They often in bereavement scrutinize the decisions they made throughout treatment as they live with a profound daily absence in their life. A family’s choice to engage in experimental treatment that is not standard care, while symptoms are unmanaged, or observing and supporting parents who refuse to disclose a diagnosis to their child, are challenging situations for a team to witness. Approaching these situations with consideration of where the family resides in the continuum of hope, acknowledging cultural context, engaging in honest dialogue with the family, and considering impact on family bereavement, while also seeking support from team members, will prove helpful in your professional and personal experience when caring for children with life-threatening illness.

Practice family-centered care - refrain from pushing your own agenda. An example of this practice, especially when introducing palliative care and hospice services, is refraining from pushing conversations about end-of-life planning details (ex., funeral planning) and signing DNR/POLST/AND orders. Coordinating care, especially in the home, requires a great deal of attention to detail and anticipatory guidance. Initial guidance and support need not focus on end-of-life details in most situations (patient does not appear to be actively dying). When end-of-life details are addressed without careful assessment of where the family resides on the continuum of hope, new and fragile relationships can be broken. Communication with the referring provider about the family’s general history, history of loss and grief response throughout illness, cultural specific considerations, and talk or lack of discussion about end of life is essential, and should take place prior to contacting any family. When a family has decided they do not want to use the word “die,” or that they have not yet told their child about his or her impending death, it is essential that the entire team, including after hours staff, be made aware of family wishes. Should a clinician observe that a child is changing significantly and may be moving to the active phase of dying, it is possible to engage a family in dialogue. Inviting parents to share what changes they are



observing is an initial step in the process of educating about end of life when a family has declined previous engagement in the conversation. Affirming their observations and offering a clinical assessment usually provides a successful movement into end-of-life discussion. Asking the question, “What has _____ been telling you” can lead to some significant disclosures, when the child is both verbal and non-verbal and/or in a semi-conscious state. The response may be, “she’s tired,” or “he wants to keep on fighting.” These responses provide another indicator of where the family is in the continuum of hope. These discussions may be initiated by any team member. When a team has had the opportunity to develop relationship with the family over time, the team should consider who might best initiate a conversation based upon the level of trust that has been developed across the team disciplines.

Promote personal control and truth telling. Deferring to parental expertise builds trust while also supporting parents and the child in their sense of control. “You know _____(child’s name) best, tell me what changes you’ve noticed and what you’ve done that has helped.” It is essential to assume that every parent is the expert on their child and then to build upon their knowledge base specific to symptom management and their experience of meaning in the situation. Children, sometimes in their efforts to protect their parents and community, may decline sharing their truth or knowledge of their situation (that they are going to die) with their family. Offering the child the opportunity to engage a variety of professionals, including social work, spiritual care, comfort therapists, hospice aides, and child life, may provide a pathway for the child to engage in expressing his or her truth with a chosen clinician and then potentially with the family. Fears about what time of death might look like are common for parents and family members. Several parents who were actively discussing and mentally preparing for their child’s time of death have reported that it was helpful to have heard, “when _____ dies, it is not an emergency.” Assuring parents that the palliative care team will support them so they can spend time holding, bathing, being with their child and family, if that is what they desire and/or is culturally appropriate, may also provide some sense of control.

Hope in Bereavement

Supporting parents in their hope into bereavement affirms the idea of continuing a life-long bond with their child. The fundamental belief that the purpose of grief is to let go of the deceased in order to move on and form new attachments is the antithesis of many bereaved people’s experience. Anne Finkbeiner’s (1996) findings demonstrate unequivocally that far from letting go of their dead children, bereaved parents strive to find ways of sustaining a life-long bond with their child. Murphy and Johnson (2003).in their study explored parental experiences when their child died a violent death. By 12 months post death 12% of the sample had found meaning in their child’s death. By 60 months post death 57% had found meaning in their child’s death. Parents who attended a parent support group were 4 times more likely to find meaning and reported lower scores on mental distress, higher scores on marital satisfaction, and higher scores in general health. Families hope throughout their child’s illness to sustain life and the physical and emotional union of relationship. That same hope seems to thrive into bereavement as family members nurture and create life-long bonds with their deceased children.

Pediatric Palliative Care Program Considerations – Supporting Hope

Pediatric palliative care providers supporting children and their families in the hospital, clinic, and community setting might consider the following program specific offerings to support the highest level of care to families amidst their changing hope.

- Anticipatory grief support (group or 1:1) for siblings and other significant children in patient’s life.
- Bereavement parent and sibling support groups/camps, or referral to groups in the community.
- Structured/intentional support for staff including 1:1 clinical supervision and weekly team meetings (separate from IDG/patient review).



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- Introduction of bereavement specialist before child's death whenever possible or appropriate. (An Australian study showed increased likelihood that parents followed up with bereavement counseling if they met counselor prior to death)
- Pediatric Annual Day of Remembrance for families and palliative care team.
- Team member's attendance at family invitational events – memorials, birthday remembrances, headstone placement events, etc.
- Creation of a Family Advisory Committee.
- Incorporating ritual and legacy projects into supportive care offered to families in treatment and into bereavement.
- Incorporating specialty programs such as animal assistance therapy and light touch therapy that support communication beyond words.
- Training of after hour's staff in pediatric end-of-life care provision.

Palliative care providers can best support families when we join as champions in their hope at time of initial contact and throughout their care as their hope changes. "(We) are not limiting factors in their sustaining hope." Joining in hope requires practice, patience, collaboration, attention to word choice, consideration of our personal and professional agenda, and the genuine intention to provide care that focuses on the best possible quality of life for the entire family. This intention is a core guiding principle of pediatric palliative care, and will be your guide in your journey with children and families living into their death amidst profound and ever changing hope.

**Hope is the thing with feathers
That perches in the soul,
And sings the tune--without the words,
And never stops at all,**

**And sweetest in the gale is heard;
And sore must be the storm
That could abash the little bird
That kept so many warm.**

**I've heard it in the chillest land,
And on the strangest sea;
Yet, never, in extremity,
It asked a crumb of me.**

- Emily Dickinson



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SILENT COMPANION

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Recently, I attended a personal spiritual retreat. When I signed up for the retreat, I knew that it was going to focus on deepening a particular prayer discipline I have been practicing for the past year. What I did not know is that the retreat was designed to be spent, mainly in silence. When we arrived on Friday evening, we tentatively made uncertain conversation with each other, probably out of the anxiousness that one feels in a room full of strangers. But later, as we learned the rhythm of how the weekend would be conducted, we were told that we would be “given permission to be with others without the need to chat.” The weekend progressed uncomfortably at first. I, for one, could talk 24 hours per day if given the opportunity. I learn through hearing others talk. I read. I write. I am not, by nature, silent. But as the two days of the retreat continued, I fell deeply into a most unexpected gift. Though we hardly spoke, the others with whom I shared meals, prayer, and community became trusted friends. There was an unspoken understanding that no words were necessary as we walked this journey side by side. We were all there to deepen our relationship to God and to participate in fairly intense self-reflection, but we were not alone. When the weekend ended, we were encouraged to talk to one another about our feelings toward each other. At first, I did not know what to say because I barely knew those with whom I had shared the past three days. Then I realized that these fellow travelers had become my trusted companions. When words are not sufficient to express all that is in the heart, another connection takes place.

Much like my relationships with our hospice patients and their families, I have discovered that walking with someone in silence, or becoming a “capable witness” as one of my colleagues calls it, has the power to create trust in ways we cannot imagine. As a chaplain, I am often left wondering, “What is my role in this situation?” More often than not, I come back to the conclusion that what is called for are not my “words of wisdom,” my insights on what God may or may not be doing, or even a verbal prayer. What is most understood and appreciated by those whom I serve are my presence and my willingness to sit, walk, or cry with them. Many of the hurts I encounter are cheapened and discounted by words that only serve to lessen my own anxiety. As a wise person once said, “Speak only if your words will improve upon the silence.” Silence is an intervention any clinician can offer in assessing the need of a patient or family.

While on the retreat, I was reminded of one of my favorite passages in Hebrew Scripture. It is from 1 Kings 19:11-12. It talks about an earthquake, a strong wind, and a fire...all powerful symbols, but the verse says that the Lord was not found in any of them, rather in the most unassuming place: a still small voice. Many times, our jobs as pediatric hospice workers are just that: a still small voice. We are charged to maintain a non-anxious presence and with continuing to be advocates for our patients and their families. These tasks may be met in a number of ways, but one of the strongest, I believe, is in the role of a silent companion. We become travelers on the journey for a time with our families and witness some of the greatest struggles they will ever face. Their pain cannot become our pain, for most of us possess our own. However, as fellow human beings first and hospice professionals second, we give immeasurable gifts simply with our compassion, empathy, and tears as we choose words or silence, all the while honoring the life-changing events to which we are witness.

Just today, I made a bereavement visit to a family who, for most of their child's time with us, was seen as “difficult.” One of the social workers once described trying to get close to the child's mother as “trying to hug shattered glass.” The parents are very matter-of-fact and were very strict on the times the hospice team could visit. The child was in the care of our hospice for four years. During that time, the family experienced many staffing changes, as well as many personal changes in their lives. They adopted another child, they drifted further from the faith they had once known, and they began to say goodbye slowly to a child who had been born healthy, the third of three boys. As he deteriorated over the years, the parents, especially the mother, became more and more immune to any and all comfort, support, or words that were offered by the hospice team. The



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team visited together at her request so that there would only be one hospice visit per week. Most of the visits were very surface, the social worker and chaplain sitting by as the nurse and mother covered the medical issues. We may touch on something the family was facing with one of the other kids, or the weather, or looking at some photographs, but for the most part, the visits were very sterile and any discussion of our patient's decline and any emotions that accompanied it were off limits. The mother would say "we know what's coming and we don't need to talk about it."

We all struggled with our roles in the home. I was allowed to come, but there was never an opportunity to do what I perceived as my job as chaplain. I never had a deep spiritual discussion with the parents, they did not want me to contact their pastor, and there were never sacraments administered. My presence in the home seemed to be welcomed, but I never "did" anything. Over the weeks, I confessed to my teammates that I didn't know what to do for this family. Surprisingly, they all expressed the same sentiment to some degree. Even the nurse felt that everything she did or suggested was questioned and second-guessed by the patient's mother, even though there was a measure of trust that eventually formed.

My growing edge in this family was made evident today. On this visit—my first since the patient's death almost three months ago—the parents cried and talked with me more than they ever had before. I realized all over again that it had been our presence in the home throughout the past four years that had made the difference. I did not come to visit as any other visitor would. I came as a professional who had seen the way they cared for their child and as someone who appreciated the grief they were experiencing. In their world, there are many people who tried comforting them with clichés, but as a hospice chaplain, I was invited in as someone who had witnessed their journey. It was as if fellow travelers had been reunited.

This family continues to teach our team how all of us can and must be willing to be a "silent companion." Sometimes, words and completing tasks are necessary. For many of us, our anxiety is the driving force behind our never-ending desire to "act" in our patients' homes and hospice rooms. But at other times—the sacred moments of this work—perhaps we need to open ourselves to our underlying task. It is the call for a reverent silence because nothing else is adequate.

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CONNECTIONS: CHAPLAINS, PALLIATIVE CARE, PATIENTS, AND THEIR FAMILIES

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The parents of baby T have just received the news that their daughter has been diagnosed with neuroblastoma. The baby is hospitalized and mom is sitting in the room in a chair pulled up next to her daughter's bed. Mom is anxious and feeling alone.

During an earlier palliative care consult, mom had said that their family is part of a large church in their home town, that they have received prayers for their daughter, but that they feel somewhat like a number given the enormity of the congregation.

The palliative care team felt it would be appropriate for their chaplain to come by and offer his services. When he entered the room, he felt anxiety and aloneness coming from baby T's mother. What followed was a classic spiritual care encounter.

In a high-tech, fast-paced hospital, it is conceivable that patients and their families might feel alone and fearful. Yes, we are in the business of providing the best highly technical medical treatment for some of the sickest children on our units. Yes, staff is busy, being sure that orders are filled, care is exceptional, and no one is neglected.

Add to this the cultural difference between what people experience out in "the normal world" and what a tertiary care pediatric hospital looks and feels like, and what you have is a "cross-cultural experience." This can feel like a foreign country where a different language is spoken and where the scenery is nothing like what it looks like "back home."

All of this lends itself to feelings of isolation and uncertainty, even under the best of circumstances. Add to that the double (or triple) burden of a life-limiting or life-threatening illness and the stage is set for fear, worry, loneliness, discouragement, confusion, and out-right panic.

When any or all of these reactions are present (and there are others like them), what is it that we have to offer? Is there a pill, a treatment or an intervention of some kind? One thing that we can offer is what is packaged in our humanity. Yes, humans are often "the best people to treat" fear, worry, loneliness, discouragement, confusion, and out-right panic, not with a pill or a treatment, but with themselves.

When I entered the room to meet baby T's mom, I brought with me my humanity and my spirituality, so to speak. In my humanity, I have the capacity to connect with Mrs. D through my body language, facial expressions, eye contact, tone of voice, vocabulary, and my overall mood. And when it comes to dealing with anxiety and aloneness, the human connection is sometimes the only thing we can offer.

Think of the times when you've been anxious and alone, whether in a hospital or sitting on a park bench. What do you find helpful? What is healing and supportive? For many (not all) it can be another caring, thoughtful, insightful, supportive human being, both at the moment and over the long haul.

The other thing that I brought with me into baby T's room was my spirituality. When defining spirituality, many people use some aspect of "connectedness." Some speak about connections with God or the divine, others about connecting with people; still others refer to connecting with nature or their inner selves.



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When I met Mrs. D, baby T's mom, my goal was to try to connect with her at as many levels as possible. I discovered that she is a very spiritual person. Her faith is important to her. She believes in a God who loves and cares for her and her child. She looks for meaning in the circumstances of life. She values prayer. And in addition to looking within, she looks to others to find support as she journeys down a very uncertain road.

When I walked into the room, I said I was the chaplain on the palliative care team and that my colleagues had asked me to stop by. I felt no resistance on mom's part. Resistance can often be as simple as, "They send chaplains to families where the patient is dying!" In the adult world, patients have often said to me on my initial visits, "What did the doctors tell you that they didn't tell me?"

As for Mrs. D, there was an openness that served as an invitation to stay and continue the conversation. I read it in her eyes. I saw it on her face. And I heard it in her voice. As much as I resist the designation that "you are a representative of God," I do confess that some people see chaplains as being connected with God and therefore my presence gives patients and families the feeling of being connected with God. I remember this most when my visits have been simple, my words brief, my input limited, but the reactions from parents have been, "Thank you SO much."

The connection that I feel with some families is simply "spirit to spirit." This just may be human spirit to human spirit, but it may also be a divine spirit that is helping two human spirits discover and experience what is unique to connecting. No one should have to take this journey alone.

For some people, this is based in their religion. For instance, having a Catholic Deacon come to give communion to a Catholic patient and/or family is a spiritual experience that also symbolizes a divine connection. Or, finding out that I am a Baptist Chaplain and this family is Baptist too makes a connection at another level. In other cases, when the family is Jewish or Muslim or of another religious background, the connection can go either way. There have been times when my Baptist Christianity is seen as "too different" and making the connection is viewed on the part of the person or family as just too difficult. I can be seen as a foreigner and they may see little potential for making a connection with someone so alien. By contrast, I recall a Muslim patient who, when I introduced myself as a chaplain from a Christian background, said, "I don't care what your background is. I just want someone to pray!"

With Mrs. D, the connections developed with my interest in her story, or better put, my interest in her child. It further developed through my empathy. I try to communicate with all of the families with whom I have contact, "What happens to you makes a difference to me." The questions I asked, the tone of my voice, the expressions on my face, the naturalness and spontaneity of the conversation all help to make an initial connection—a faith connection.

In the middle of a dangerous, life-limiting or life-threatening setting, having a faith-based resource is very important to many people. They see the world through eyes of faith and knowing that what is spiritual is respected, that they will be prayed for, that a reminder of God's presence is visible and available are all significant coping resources to people for whom "life is tumbling in."

With Mrs. D, there were many questions. "How do I know what to do?" "How will I know what to say about treatment options?" "How will I know when my child is coming close to the end?" The connections were made through these questions, not so much by giving answers but by giving room for the questions to be asked and with follow-up questions to invite her to move even further into these frightening and threatening areas.

The questions are usually followed up with prayer. What is it about prayer that helps those praying connect with each other and with God? My experience is that I can say the same thing in common talk, and I can say "Can we pray about that?" and say just about the same thing, and the connection with the latter be even deeper. That is true for those who are faith-based and occasionally I have found it true for people who would say they are just "searching."



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Connections also occur between families and other staff members. During one visit, Mrs. D confided in me that she was anxious over her daughter's disease trajectory and she thought one of our Palliative Care physicians had given her a brief explanation some weeks back. I offered to contact that same physician to see if he could see her that day and a quick page helped make that happen. Mrs. D was grateful.

Connections occur in even more tangible ways: providing a map of the building, escorting a family to the cafeteria, explaining where the local grocery stores are, supplying a copy of a Bible, the Qur'an, or the Book of Mormon, or even going down to a test with a child when the parent just can't be present at the hospital when, for instance, one of their other children is sick at home.

Murray and Zentner state, "The spiritual dimension tries to be in harmony with the universe, and strives for answers about the infinite, and comes into focus when the person faces emotional stress, physical illness or death" ¹. The illness of a child certainly causes disharmony within the universe of any parent, often bringing with it a good deal of emotional and spiritual distress. Chaplains are ones who try not to give answers, as much as some people strive for them. Instead, our goal is to be a palliative presence for all those patients and their families with whom we come in contact. For in the words of Joan Halifax, quoted in a Pythia Peay's article, "There is not much we can explain, but there is a lot we can be" ².

As for baby T, her last chart entry reads, "Since her last clinic visit in April, she has been doing well and does not have any complaints." Her parents are appreciating every day that baby T is with them. As mom said on one occasion, "This child is for us a gift from God." Yes, there are still days of anxiety and loneliness. But there are also many days of gratitude and appreciation. Much of that we attribute to a set of parents who tried to stay connected with each other (and that is not always easy), to reality (as best they can understand it), to good medical care, and to the inner depth of their own spirituality that has sustained them (and we hope will continue to do so) as they move through a very uncertain future.

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TRANSITION FROM HOSPITAL TO HOME HOSPICE CARE: A CASE STUDY

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Liam, a Caucasian male was born with a rare chromosome translocation, at 39 weeks gestation by repeat C-section. Liam's translocation was diagnosed in the prenatal period by amniocentesis after routine screening fetal ultrasound found multiple congenital anomalies. The prenatal diagnosis of the rare chromosome translocation allowed an opportunity for the family to develop a Birthing Plan in which they choose to forgo life prolonging measures. The family was told that Liam may not survive more than a few days after birth. Liam's APGARs at birth were 8 and 9. His examination after birth confirmed the prenatal abnormalities including arthrogryposis and cardiac, renal, and central nervous system abnormalities. Initially, he was able to breast feed, but he would soon tire and need to be fed by a nasogastric tube. Several days into his NICU stay it was apparent that Liam may survive longer than expected and a consult for hospice was requested by the neonatologist. The hospice team comprised of a pediatrician, nurse, and social worker met with the parents. The team identified the family goals of allowing natural death, with a focus of comfort care for Liam and to spend quality time together as a "normal" family. The family included both parents and Liam's 4-year-old sibling. The parents had some support from their church and friends but the extended family lived out of town.

Hospice administration obtained information on the father's hospice benefit provided by his private insurance. The family was educated by the hospice nurse and social worker on what services, medications, and equipment would be covered when selecting the hospice benefit, as well as which services were not covered. The family was further educated and offered support that they could revoke the hospice benefit if they decided to pursue more aggressive treatment or curative procedures. The family elected to sign a home/state Do Not Resuscitate (DNR) form and the hospice team discussed different scenarios and options that might unfold when invoking the home DNR. Medical equipment provided included oxygen and related supplies, suction machine, and feeding supplies. Medications ordered included Ativan and morphine for end-of-life symptom management. All medical equipment and medications were ordered through the hospice durable medical equipment and pharmacy and were brought to Liam's home before he left the nursery.

The hospice social worker discussed financial issues with the family and assisted with appropriate community support referrals. Though the family had spiritual support through their own church, the hospice chaplain was requested by the parents to make home visits along with the social worker to assist in counseling the 4-year-old sibling. The chaplain and social worker (a mental health counselor) counseled on issues related when bringing Liam home and preparing for grief, loss, and bereavement. Arrangements were made for the hospice child life specialist to visit the sibling once the family was at home. The family was educated on how certain things unfold when a death occurs in the home including: who is called, options for calling "911," the need to consider a funeral home, and the 24/7 availability of the hospice staff to be in attendance and offer support to the family at the time of death. Medical management would be provided by the hospice physician initially with the option of selecting a primary care physician in the community after discharge from the nursery. The family chose to have the hospice chaplain baptize Liam prior to his discharge home. Liam was discharged home as a hospice patient at nine days of life.

Liam had several subsequent admissions to the local children's hospital for pneumonia, suspected to be related to aspiration. He was unable to tolerate advancing volumes of nasogastric feedings. During a hospitalization it was offered to the family to have a tracheostomy and gastrostomy feeding tube. The hospice team supported the family through evaluation of these options. The family decided they did not want to put Liam through surgeries that would not change his outcome. The hospice nurse and social worker visited the family at least



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weekly. The hospice chaplain and child life specialist visited every other week. The hospice physician was available for consultation to the hospice nurse and the family by phone and visited Liam at home at least once a month. Liam died when he was 5 months and 2 days old. The hospice nurse, social worker, and physician arrived at the family's home shortly after the early morning death of Liam. The hospice chaplain also made a visit to the family on the day of Liam's death. The social worker assisted the family in arranging out of town burial services. The hospice chaplain assisted in Liam's memorial service at the family's local church. The family continues to use hospice bereavement services.

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LEAVING THE HOSPITAL: ROADWAYS, ROAD BUMPS AND DETOURS

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Due in part to medical advances that are bringing many changes to how children are cared for outside of the hospital setting, an increasing number of parents (or family caregivers) are providing hands-on care for children with chronic and complex illnesses. In fact, five million children in the United States have limitations of activity because of a health condition, with the number of chronically ill children being even higher.¹ This population is also growing older: more than half of a million children with special health-care needs turned 18 years of age in 2002, and this number is expected to remain steady for the foreseeable future. The 2002 cohort represents the first generation of children for whom medical technology is allowing survival with conditions that, until recently, would have killed them in infancy or early childhood. The influx is straining an already-burdened health care system, and patients and their physicians are feeling the added stress, according to a study by researchers at the University of Florida's Institute for Child Health Policy.²

The number of children living with a chronic illness will likely further increase because of medical advancements and genetic, social, and behavioral changes.¹ When their child has a sudden change in health status or is diagnosed with a chronic and potentially life-threatening disease, caregivers and those around them experience monumental life stress.³⁻⁴ The emotional as well as physical impact on family caregivers influences every aspect of family life.⁵

The care of a chronically ill child involves not just managing complex medical interventions, but also balancing the issues of everyday life. As more complex care is moved from hospital to home, caregivers must meet their child's physical needs as well as their emotional and spiritual needs. The responsibility of addressing these needs falls first to primary caregivers, but also involves school personnel, family friends, and siblings. Combining care of a chronically ill child with family life, in combination with managing the consequences of the illness on siblings and the usual stressors of family life, career, and social life, can be a burdensome task for parents.⁶⁻¹⁰

While juggling these varied and complex tasks, some parents experience a lower quality of life together with increased physical and emotional strain.¹¹⁻¹² In addition, parents have reported that their own physical, emotional, and social health influences the health and well-being of their children.^{4,13} This presents a conflict. As it becomes increasingly more difficult for parents to manage all of their caregiving responsibilities, their ability to care for themselves suffers, which in turn affects the health and well-being of all members of their family. Hospitalization of a child further throws the family structure out of balance. Outcomes of hospitalizations can vary greatly, ranging from a return to the child's baseline status, an increase in medical needs, or a final decline toward the child's end of life. In the course of a hospitalization, some families may find that having their child return to the home is no longer feasible. Thorough discharge planning and offering realistic post-hospitalization options are pivotal in helping regain the balance between the illness of the child and caregiver well-being.¹⁴⁻¹⁵

As mentioned earlier, going home from the hospital can be an emotional experience for families with children who have complex medical needs. Parents are often torn between getting home as quickly as possible while



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feeling unprepared and uncertain about their ability to deal with new issues or equipment that has been added to their child's health care regimen. Preparing for discharge is not an event, but rather a continuum that begins at admission. Approaching the care of children with chronic and complex health needs with a transdisciplinary point of view accommodates the multiple needs of the child, allowing for a smooth transition to home. This involves incorporating the expertise and input of parents/caregivers, doctors, advanced practice and registered nurses, social workers, dietitians, home-care professionals, and, at times, hospice into the individualized plan of care tailored for each child.

Creating a hospital discharge plan can seem complicated and overwhelming. Planning ahead and using the many resources available can improve quality of life, reduce fear, and enhance the confidence of families, friends, and patients. This confidence can be enhanced by building rapport and trust in developing relationships between healthcare providers and the family. Of crucial importance is to assure families that they are leaving the hospital, not their medical support system or palliative care team.

The first step is to look carefully at what the family already has in place at home and strategize what changes, if any, will need to be made. Performing a complete assessment of needs and establishing goals of care while the child is hospitalized can help anticipate problems and avoid readmission to the hospital. Establishing goals of care will dictate not just what children need, but also where they might be going after discharge. Going home with increased nursing or hospice care, going to a short-term rehabilitation facility, or even long-term placement are all realistic and loving options for the care of children with chronic health care needs.

Each person requires different types and amounts of care. Once the specific needs of the child are clarified, it is important to consider, realistically, the energy and time available from the child's support systems. When the family is the main source of care, their employment, health, other children, and responsibilities must be considered. If there is more than one adult caregiver, a schedule to rotate responsibilities should be worked out. If only one person is the main caregiver, he or she must be allotted some free time for physical and mental well-being, if available. Professional nursing in the home is a reality for many palliative care patients. Helping families understand the benefits as well as the burdens of having professionals moving into and out of their home regularly can help reduce the stress of new and changing situations. Infants and growing children, teenagers, mates, and parents may cause competing demands, so the psychological strengths of both the patient and the family helpers must be considered.

While many palliative care patients have families who have already adapted to the added demands of a child with chronic and complex health needs, planning for additional training while in the hospital works to build confidence in new tasks. Assessing new equipment needs and finding suppliers can be daunting. When the call comes to the homecare agency regarding getting a patient home, numerous things must be determined before initiating the home-going process. Assessing the medical and educational needs as well as the ability of the family to follow through with the plan of care is a good starting point.

In addition to having a desire to care for their child at home, families must understand the reality of the challenges that will arise. Suddenly their home—their safe haven and their refuge in the storm—becomes a mini-hospital. Multiple people will be coming into their home: nurses, supervisors, equipment delivery people, therapists, and their supervisors, to name a few. Many times on many days there is someone in the house who is not family. Every move that is made is scrutinized, and every argument is heard by someone outside of the family. There is no privacy, and mixed emotions are common: resentment that others are there invading privacy; feelings of guilt at not being able to manage all of a child's care needs; honest acceptance that one person cannot provide all of their child's care; and even relief that help has finally been put in place.

Case Study

In 1985 Victor was an active 7-year-old who went out to play with his neighborhood friends in a nearby canal. Victor fell into the canal and wasn't able to get up. Summoned by the friends Victor was playing with, Victor's mom, Joy, arrived to find him unconscious and not breathing. Over the next several weeks in the hospital Victor required a tracheostomy for breathing, a gastrostomy tube for feeds, and round-



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the-clock care due to the magnitude of his injuries. Despite the opinion of the medical profession that Victor would be better served through placement in a facility, Joy worked diligently to learn what his care needs were and how she could provide for those needs. For the next few years, Joy, a single mother of 5, provided for all of Victor's care and continued to hope for a miracle. She worked with Victor to develop a way to communicate using eye blinks, made certain that his range of motion was done daily, and followed up with the medial team as needed. After approximately 4 years, Joy agreed to private duty nursing to help with the care that was needed. While having help to care for Victor was a blessing, it also brought about a whole other set of issues. Staff who weren't able to respect the privacy of the family, who criticized the family for choices they made, and who didn't want to enter the neighborhood were all added stressors. Joy worked through these issues as diligently as she had worked through the initial 4 years alone. Over the ensuing years there were many hurdles to face, many illnesses that Victor conquered, and many surgeries that he recovered from. In 2003, a nurse that Joy trusted and respected suggested that she get involved with the palliative care team at Akron Children's Hospital, not because Victor was dying, but because of the complexity of the care that he required. Joy politely but emphatically declined since she was certain that palliative care meant giving up. Over the next couple of years the topic was broached on occasion, both at times of illness and at times of health, without any acceptance from Joy. Several of her long-term private duty nurses would also mention the benefits of palliative care from time to time but Joy refused to budge. Finally in 2005 she agreed to meet select members of the team, and allow them to help with Victor's care on her terms. Team members were patient and accepting of Joy and her need to be in control; they were available for support when called upon, but didn't force things on the family. Recently, Victor has been showing signs of decline, so hospice was presented to Joy. Because of the trust that she has in Victor's care from the home health agency and the palliative care team, Joy agreed, and this new relationship is progressing well. Throughout this family's journey, one care team has not replaced the other; all are involved to support the family completely. Most importantly to the family, the many layers of support through coordinated care have allowed him to remain in the loving care of his family at home.

Home-going needs are numerous and require coordination of care on many levels. Check lists, protocols and care plans are helpful to keep members of the healthcare team, as well as members of the family, organized and on task. Of particular importance is proactive consideration of medications that need to be available in the home. Prescriptions are not sufficient; families also need to be given written administration schedules (and/or pre-filled medication boxes), written indications for each medication (especially those that are PRN) and detailed explanations of possible side effects. Careful preparation will lessen unanticipated phone calls, emergency room visits or readmissions to the hospital for issues that could have been managed in the home, and will result in improved comfort and self-efficacy for caregivers.

While every hospital has individual protocols for helping families move from hospital to home, there are a few guidelines that are consistent. Appendix A is an example of an educational tool written in common language to help parents prepare for going home with their chronically ill child. The information is from Akron Children's Hospital and is specific to the state of Ohio but can be generalized.

As is well-known in the pediatric palliative care and hospice community, the unfortunate truth is that children sometimes decline and die from their underlying conditions. Like pediatric palliative care, most pediatric hospice programs do not require a family to forego life-sustaining or cure-directed therapy in order to benefit from services and support in the home, but myths surrounding pediatric palliative and hospice care are still rampant. It is important for trusted caregivers in the hospital or the home to develop language to explain to families that recognizing that a child has a life-limiting illness is not giving up hope. Instead, this acknowledgment allows for opportunities for the child and family to direct their hope and goals of care in realistic ways.

Case Study

Jake is a baby boy who contracted toxoplasmosis during his mother's pregnancy. He is in the guardianship of his grandparents. During a hospitalization, it became clear that Jake's ineffective breathing was caused by damage to the area of his brain that regulated his breathing. Many meetings



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among his medical team provided several options for Jake's care, but none of them, ultimately, would save Jake's life. The option of having tracheostomy and ventilator support was explored, but the family felt it would not be in Jake's best interest and instead chose to take him home. The palliative care team was notified late on a Friday afternoon that the family wanted to take their baby home NOW. Through the coordination of efforts of the primary medical team, palliative care, nurse case managers, and a pediatric hospice team, the family was able to have their wish come true. The pediatric hospice nurse was waiting for the family as they arrived home within hours of the initial call. Medications for comfort as well as oxygen supplies were delivered to the home. Jake was not expected to live through that weekend, but with the love and support of his family and the comfort supplied by his hospice staff, Jake is still enjoying time with his family many months later.

While many hospice providers have historically focused on the adult population, pediatric hospice services, from both pediatric-specific hospices and general hospices with individuals trained in the care of children, are increasingly available. The following link to one active and well-established pediatric hospice program explains how pediatric hospice fits into the life of children with complex and chronic illnesses:
www.hospicewr.org/template.asp?id=75.

To provide comprehensive services, hospital-based palliative care programs need to partner with many community services, including adult hospice providers. One way to bridge the gap between pediatric and adult care is to bring the organizations together on a regular basis for teaching and networking. A single set of pediatric admission orders, to be used by different organizations caring for pediatric patients, can increase patient safety and communication among providers. Appendix B is an example of a collaborative set of admission orders that is used for all patients going home from the hospital with hospice care from Akron Children's Hospital, regardless of the agency involved. This order set was designed over a year's time with input from multiple partnering agencies, to streamline communication and decrease the chance that medical errors will occur in the transition.

There are times when having a child return to the family home is not possible. Of course, this decision is never made lightly by caregivers or medical providers. Honest evaluation of what families can and cannot provide is a difficult task. If the decision to move a child to a long-term care facility is made, helping families find the "right fit" for their child is very important and entails knowing what area resources are available. Options for children or young adults with medical technology (such as tracheostomies) may be more limited. Prepare for transition early if a child is likely to live into an adult age and you live in a state that requires people to transfer to adult facilities at certain chronological time points.

Case Study

Jason is a 25-year-old who was adopted when he was 2 years old. He had suffered hypoxic ischemic injury to his brain at birth. He was one of two children adopted by his parents. His sister also had profound intellectual disabilities and was non-verbal and non-ambulatory. Jason required very little in the way of medical intervention as he grew up; besides a seizure disorder, he enjoyed a state of relative wellness for most of his life. Jason's parents were both in their mid 60's when he was admitted to the hospital with aspiration pneumonia. It became clear that Jason was refluxing food into his lungs (silent aspiration); while waiting for surgery to fix the problem, he had a very large aspiration that caused profound lung damage so severe that he needed a tracheotomy. Initially, he was able to go home, but it quickly became clear that his parents were no longer able to care for him due to their advancing age, and further complications began to set in. Because of insurance issues, home nursing was not an option for this family. Jason returned to the hospital with a severe bedsore and pneumonia. After an extended stay and several complications Jason's family made the loving, but heart-breaking decision to allow Jason to be cared for at a long-term care facility for children with special needs. The palliative care social workers and case manager helped the parents with the change to their family routine, helped them to become comfortable with Jason's new home, and often transported them to see their son. Jason thrived in his new environment, and his parents were able to visit him and enjoy just being his parents without the added difficulty of being his caregivers.



An illness in a family can bring back old thoughts, feelings, and fears. Anxiety long-forgotten can rush back as changes to a child's health status occur. Connections between those past events and the present situation may not be immediately apparent to caregivers or health care providers. As family/caregivers assume new responsibilities, feelings of anger, resentment, and guilt can surface about these new obligations. Limitations on activities, changes in appearance, loss of physical control, and ongoing pain are frustrating to have and to experience through a child. Healthy siblings may have feelings of anger, resentment, and guilt and need support as much as adult caregivers. Fears about the future should be discussed openly to keep family members from becoming isolated. The services of a social worker, chaplain, or psychologist can provide a platform for families to work through these difficult issues both in and out of the hospital setting.

Summary: There are many options for families when taking their child home from the hospital. No matter what choices are made, keeping the lines of communication open and problem solving each issue as it arises, will help families with their ongoing responsibilities. Giving family's opportunities to talk to their providers openly and honestly, and providing easy 24-hour access to trusted team members, can stop problems before they happen. Coordination of open and timely communication among providers and agencies is essential to provide the best support possible. When all the support systems come together with a single focus on the well-being of the child, smooth transitions are not only possible, but happen every day.

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APPENDIX A

HOMEGOING INSTRUCTION SHEET

Planning Care at Home

You have the right to choose the home nursing and medical equipment company for your child's care from available qualified providers. Ask for the Home Health Care handout for selection tips and an Ohio provider list.

- A social worker or case manager can help you verify your family's insurance benefits, other available funding sources and any approved list for home nursing care and home medical
- Nurses usually complete shifts in eight-hour intervals. Carefully consider the time of day (day, evening, night) that will be most helpful for nursing care.
- The home medical equipment company will provide medical equipment and supplies needed at home.

Home Health Care Funding: Ohio Medicaid

The Ohio Home Care Waiver (Ohio Medicaid's program of home care services) or Early and Periodic Screening, Diagnosis and Treatment (Ohio Medicaid's HealthChek Program) provide funding for home private duty nursing to qualifying families. An Ohio Department of Job and Family Services coordinator determines whether the program will fund hours and the specific hours the programs will fund for your child's care based on an assessment. If nursing hours are approved, children receive at most eight hours of nursing care a day when first home from the hospital. A social worker will give you a waiver application and is available to help you complete it if needed. Start the application as soon as possible. A social worker will fax the application to the state agency.

The Ohio Department of Job and Family Services will contact you for an appointment. Make it clear that you are requesting services for your child under Ohio Home Care Waiver or Ohio HealthChek.

Ohio Home Care Waiver or Ohio HealthChek
Ohio Department of Job and Family Services
Phone: 614-466-6742
Medicaid Consumer Hotline: 800-324-8680 or 800-292-3572 (TDD)
Fax: 614-466-6945
E-mail: BHCS@ODJFS.state.oh.us
Web site: <http://jfs.ohio.gov>

Planning Ahead for Success

- Your family caregivers and back-up team must be ready, willing, and well-informed about the child's care.
- Your family must become very good at planning ahead and organizing.
- You must have running water for care and a phone for emergency use.
- You need access to emergency medical services and transportation. Hospital staff will inform your local ambulance company, emergency medical services, fire department, and hospital emergency department of your child's needs before you leave the hospital.

Emergency Plan

- Always have your travel bag which includes the self-inflating bag, mask, an extra tracheostomy tube with obturator, ties, and scissors handy both at home and away from home.
- Make a back-up plan in case the home nurse calls off.



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- Post the CPR steps where they will be handy in case of an emergency.
- Notify your electric, gas, and telephone company that you have a child with a tracheostomy so that your home is a priority in resuming service in the event of a power outage.
- Keep a list of emergency numbers by the phone.
- If snow is a problem in your area, notify your Department of Public Works for snow removal priority.
- A medical alert bracelet may be helpful.

We want to inform you about care needs using clear language that you understand. We also invite you to ask questions about your child's care when you do not understand or something does not seem right. You deserve the safest care. For more information or information in another language, call the Family Resource Center at 330-543-8180.

Supervision of In-home Help

Set clear expectations for home care staff who assist with care. This will help you and the home care staff work together as a team to create the best outcome for your family. Discuss your ideas about use of the home phone, discipline of other children in the home, and communication between nursing shifts about the child's status. You may want to prepare written notes on your child's status and ask each nursing shift to do the same. Using this method, early signs of trouble can be recognized and timely medical help can be obtained. A patient journal also provides a way for nurses and family members to communicate about various issues.

School Education

Work with educators to develop appropriate activities for a school-age child's abilities and needs. Your child may attend school with some support when stable on portable equipment. The Ohio early intervention program provides a home-based educational and therapy program for babies and young children.

Support for Parents

If you feel overwhelmed by medical care responsibilities and isolated from other people because of the demands of home care, your case manager or hospital social worker can help you locate appropriate help. Help may include support groups, the hospital Parent Mentor Program or community resources. Many caregivers find it hard to leave home to attend meetings. Support from other family members, neighbors, friends, and relatives may be needed. They may rely on this network for grocery shopping, errands, household help, and companionship. Some positive things you can do while your child is in the hospital:

- Visit as often as possible. Your child needs to see you, hear your voice and feel your presence.
- Ask staff about times for siblings to visit.
- Follow staff instructions about washing hands or any other intensive care unit requirements.
- Ask questions. Learn as much as you can about your child's condition and progress.
- Talk with other families in similar situations. You can learn a great deal from each other.
- Take breaks to allow you to recharge.

Questions and Concerns

All health care providers caring for your child welcome your questions. Ask to speak to the health care provider coordinating your child's discharge plan:

Name: _____ Contact Number: _____.



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A SIBLING'S GRIEF: CONSIDERATIONS TO BEST SUPPORT A CHILD FACING LOSS

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Significant changes in life initiate a grief response that relates to the losses involved. Grief and loss are a part of our daily lives, even the lives of children. Loss happens through endings, changes, and transitions. Loss can be the goldfish that died when you were in second grade or the divorce your parents went through when you were 9 years old. Some losses are bigger than others and have a deeper impact on our lives. Some of the most significant losses can be the serious illness or death of a loved one. When the sibling of a child is seriously ill or dying, a child's life will never be the same.

Many adults find the concepts of grief and loss uncomfortable; feelings that are easier to push aside and ignore. This can be particularly true for adults who are caring for children experiencing loss. Adults often express the desire to "take the pain away" if they could. However, when a significant loss occurs in a child's life, the reality is that child will grieve and will experience pain. In an effort to protect a child, an adult may unintentionally limit a child's ability to process the change or loss, and therefore, not allow a child to move forward in a healthy way.

By increasing our own understanding about how children experience grief and loss, we can better assist children through the normal and necessary process of grieving. This article addresses the significance of an illness or death in a child's life and the grief reactions that may occur. It also emphasizes helpful considerations when a child's sibling is seriously ill or has died. Finally, the article includes tools and verbiage which can assist both professionals and adult caregivers to best support children facing such difficult situations in their lives.

General Overview of Children and Grief

Children grieve as part of a family. When a loved one is diagnosed with an illness or has died, it affects the way in which the family functions. Family roles and responsibilities may adjust to accommodate the new needs in the family structure. Children may grieve not only that a loved one is ill, may die, or has died but also for the secondary losses which follow. These losses may include 1) changes in daily routine, 2) decreased attention or availability of adult caregivers, 3) increased individual responsibilities within the family and 4) the inability of the person who is seriously ill or has died to be able to play with the child as in the past. Often when the serious illness or loss is related to a sibling, adult caregivers are no longer as emotionally available to the other children in the family. A heightened awareness of this reality by adult caregivers can be helpful as they may want to seek additional support.

Children re-grieve. Children work through their grief in cycles. Each time a new developmental milestone is attained, children will integrate and use their newly acquired skills to gain further understanding of their grief. The child's history of loss and coping strategies as well as age and developmental stage will affect his or her re-grieving experience.

Children are often repetitive in their grief. A child may ask the same questions repeatedly as a way to understanding the illness or death. Answering a child's repeated questions with the same information gives the child a sense of stability, consistency, and trust in his or her relationship with the adult caregiver.

Young children are concrete thinkers. Adults frequently use euphemisms when describing an illness, death or dying to soften the blow of this harsh reality. Adults need to be careful when using euphemisms so that children don't become increasingly scared or more confused. For instance, if an adult says, "We lost your brother today," a child may want to know why people aren't looking for him. A child may also wonder, "If I get lost, will anyone come looking for me?"



Similarly, an explanation like “*Your sister is sleeping peacefully now,*” may create a fear of going to bed at night.

Children often have “magical thinking.” Because they are focused on themselves, children often have the sense that they have the power to make things happen in their lives and may feel responsible for a loved one’s illness or death. Adults can convey to children that thoughts and feelings are not powerful enough to cause sickness and death. It is important to emphasize that what is happening or has happened is no one’s fault.

Children often worry about their own safety. Again, with the focus on self, children often worry that they too or someone else they love may die. Additionally, they worry about how their own care needs will be met.

Children often have regressive behaviors. Children often revert to behaviors that they may have previously outgrown (i.e., bedwetting, thumb sucking, etc). This is a common and normal expression of grief in children of all age groups. An adult caregiver need not have excessive concern because usually regressive behaviors are short lived.

Developmental Considerations

Newborn to age three: No matter how young, children can sense when things in the family routine are disrupted. They may notice: presence of new people, the sudden absence of a significant person, sadness or anxiety, and/or adult caregivers being gone at odd times. The child’s reactions to these changes often manifest behaviorally and may include altered eating patterns, fussiness, and/or disrupted sleep schedule. These responses will be intense but brief.

Ages three to six: Children in this age group may think they are responsible for the person’s illness, or, if they are good enough, their loved one will become healthy again. They will ask repetitive questions about how and why their loved became sick and/or died. Responses to a loved one’s illness or death will come in spurts and may include: nightmares, confusion, and regression. When a loved one dies, these children will not understand the concept of finality and believe that death is reversible or temporary. They will ask questions about the dead person’s return or may not seem to really be affected by the death at all since they expect the person to come back soon.

Ages six to nine: Children in this age group will have a morbid curiosity of what is or has happened and may ask for more details regarding a serious illness or cause of death. They may view all illness as something that is contagious and therefore may not feel comfortable in the room or home with someone who is ill or has died. Feeling responsible for the death is still a possible reaction at this age. Social development is occurring during this stage so children will watch adults to see how they should respond to a particular situation. By age 7, children usually begin to understand the finality of death.

Ages nine to twelve: Children in this age group may experience a broad range of emotions in response to their loved one’s illness or death that may include shock, denial, fear, anger, guilt, depression, and even withdrawal. Though these children are better able to articulate what they are feeling, they will benefit from adults who can share their own thoughts and feelings. Because children this age are more aware of social pressures, they may feel concerned about how to act or grieve and still fit in with their friends. They may struggle to concentrate in school and may have difficulty completing assignments. They may either withdraw from peers or act out with negative behaviors. Additionally, children are more aware of the impact that a serious illness or death may have on them and their family. This increased understanding and awareness of the complexities of grief may take a toll physically and lead to higher susceptibility to illnesses or other ailments such as headaches or stomach aches. As a rule, the concept of the finality of death is grasped by this developmental age.

Ages thirteen to eighteen: By the teen years, most children have the ability to think abstractly and can truly grasp the reality of serious illness and death. Their reactions may be very much like any adult but don’t assume that these children can handle it all on their own. It is still necessary for an adult to have open discussion about



illness, death, and the family's responses. Teens will also seek answers for why their loved one is ill or has died. They will likely search out the meaning of life and death in an existential manner, perhaps for the first time. There will be a physical component to their grief which can include being tired, having problems concentrating, and being more susceptible to illness, which may create difficulties for the teen in meeting expectations at school regarding attendance and classroom performance. Anger (toward parents/caregiver, self, person who died, medical personnel, etc.) may result in noncompliance or acting out. Depression may surface more strongly with thoughts of suicide (desire to join the one who died) being present. Your teen may withdraw emotionally from you and/or socially from friends and activities. Eating and sleeping patterns may change drastically. Teens may seek out ways to escape the pain of grief by engaging in high-risk behaviors such as alcohol and drug use, reckless sexual activity, and driving dangerously. Teens may be more willing to talk and share their feelings with others outside the family.

General Considerations When Working with Children and Families in an Anticipatory Setting

When talking to children and families about the serious illness or even death of a loved one, the following questions are important to consider and will need to be assessed.

- What has the child been told about the disease, prognosis, etc.?
- What is the comfort level of the parent(s) with the child knowing details about the disease, prognosis, etc.?
- What is the culture in the family regarding illness, speaking openly, and sharing difficult things with children?
- What is the child's history with death (other family members, friends, and pets)?
- What are the family and child's coping responses related to illness and death?
- If the patient is not living in the same home as the child, when was the last time the child saw the patient?
- What does the child know about the disease?
 - Has the child attended conferences with the doctor?
 - Has the child accompanied the patient to treatments?
 - Has the child visited the patient in the hospital?
 - Has the child assisted with any care giving?

Some families may find it hard to speak with their children about a serious illness or death. If a family chooses not to talk with a child about what is happening:

- Always consider the culture of the family, including ethnic and religious beliefs and practices.
- Educate the family that the child may overhear conversations and imagine things that are worse than the truth.
- Children may also be picking up on the emotional atmosphere in the home and the changes in lifestyle that have occurred as the family has adjusted to the illness.

Topics to Address When Telling a Child of a New Diagnosis of a Serious or Terminal Illness

When consulting with an adult caregiver of child about ways to best support their children when they have difficult information to share, it is helpful for the professional to keep the following in mind. First, primary caregivers know their children best. They will be able to anticipate the best time and setting to share difficult information and can also imagine what their child's greatest fears might be. Knowing this, a professional can reinforce the caregiver's intuition about when and where it's best to initiate this conversation and what initial fears to address.



Adults often worry about what the impact of showing their own emotions will have on a child. A caregiver's open expression of feelings can actually give children the confidence to be able to share their own feelings. Therefore, it is beneficial for adults to be open with children about feelings they may have and the reasons for having these feelings. A caregiver may say, "*I might cry as I try to tell you this because the news makes me sad.*"

The following are important considerations to address with adults in this situation:

Inform the child that there is important information about the medical condition that needs to be shared with them. This honors the child's importance in the family. *Example: "We took your (sibling) to the doctor today, and the doctor told us some hard news about your (sibling's) illness. It feels important for us to share this information with you."*

Allow some choice and control about when the child would like to hear the information. Some children may need a break after simply hearing that there is hard news. *Example: "Would you like for us to talk about it now, or would prefer a different time?"* Again, adult caregivers will know the most comfortable time to introduce this conversation. Examples may include: dinner, bedtime, or driving in the car.

Tell the truth using correct medical language. *Example: "You know your (sibling) has been taking a medicine called chemotherapy. The doctor told us today that your (sibling's) cancer is still growing and the medicine isn't working anymore. Your (sibling) is going to die from the cancer."*

Answer a child's questions. Provide honest, simple answers. If you don't know the answer, it is okay to say, "*That's a really good question, but I don't know the answer either. Would you like for me to try to find out some more information about that for you?*"

Reassure children that their needs will continue to be met by the people in their lives who love them. Children may need to hear names of these people, and should definitely be told if there will be significant changes in their routine. *Example: "You know grandma has been staying with us and helping while your (sibling) has been sick. When your (sibling) dies, she will continue to help me take care of you."*

Causation and contagion. Remind children that they did not cause the illness, and if it is true, that they cannot catch the illness. *Examples: "It's no one's fault" or "Remember that nothing anyone did, caused your (sibling) to get sick." "Always remember that his (her) illness isn't anything that anyone can catch."*

If a sibling is discharged home from a hospital setting, be aware that keeping the well child's routine as normal as possible is helpful. Talk openly about any changes children may see in their routine. It is also good to find ways to involve the children in simple care giving tasks.

Professional support of a grieving sibling

When adult caregivers involve a professional, it is important that they clearly set the stage for the initial visit. Adults may need to be given the words to explain the professional's presence. They may consider avoiding the use of the word "counselor" as children may not want others to think there is something wrong with them. A simple introduction may be "I'd like for (professional's first name) to come and talk with you because she/he has spent time with lots of other kids who have a sick (brother/sister) and can be helpful during this hard time."

General Framework for an initial contact with children:

Clearly identify the professional role. The professional may start the conversation by asking a child, "Did your Mom and Dad tell you I was coming to see you", and if so "Did they tell you why I came to meet you?" Explain the reason for the visit and the supportive role for children that the professional has on the palliative or hospice team. "*I have the best job on the team. I get to hang out with kids who have a bother or sister who is really sick.*"



Assess the child's understanding of illness. A gentle way to begin is to first explore the **CHANGES** children have noticed in the family or the changes they may anticipate. Discuss how a child has received information thus far and how he or she wishes to receive support or important family information in the future. If a child's understanding is limited and the child would benefit from receiving more information, the professional may assist in facilitating an appropriate way for the child to attain further honest and clear information.

Expand the conversation. Allow the child to tell the story from his or her own perspective. This will give insight into how the child is processing what is happening in the family. Try to keep an awareness of **FEARS** that a child may express that need clarification.

Normalize the child's experience. It is helpful for children to understand that they are not alone. One way to reinforce this is by letting a child know that as a professional, you have met other children who have had a loved one die and are grieving. Reassure them that other children describe having very big and sometimes confusing feelings when something this hard has happened in their life. Each child's grief process is unique and all their feelings are okay.

Validate healthy coping. Ask children about the activities that they enjoy doing and/or make them feel better. Encourage the importance of these activities as methods of coping.

Discuss inclusion of children in care giving. Engage the child in conversation about ways that they can help their sick or dying loved one feel better. Always consider a child's comfort level and give simple, concrete tasks. Make sure that children are successful in any task they perform. Examples of simple tasks include reading a book, playing games, watching TV, giving hugs and kisses, holding hands, covering the ill person with a blanket, or bringing him/her water/food. The most important consideration is that the relationship between the child and his/her ill sibling is honored.

General ideas for repeat contact with children:

Simple legacy building activities that can be introduced to parents:

- Create a mobile to go over the bed of the loved one who is seriously ill.
- Draw pictures and make cards for the wall.
- Complete a family affirmation project. Have each family member trace their hand on a piece of construction paper. On each finger, ask each family member to write about what they love about each person in their family or the things they enjoy doing with one another. The handprints can then be decorated, cut out, and put on a big piece of poster board.
- Create a memory book or story of the family.
- Create blankets or pillows out of loved one's clothing.
- Decorate picture frames to put pictures of children with their loved one who is ill.
- Decorate candle holders to honor a loved one who is ill.

Important considerations if prognosis is short and death is imminent

Many adult caregivers have anxiety about the most appropriate way to communicate that a brother or sister is dying. However, children have taught us how important it is to them to fully understand what is happening, even if it is hard, so that they can make choices to best take care of themselves. As they continue on their journey through the grief process, the way they are honored surrounding time of death details makes a significant difference in their ability to process the event and to move on with their life in healthy ways. A simple way of stating the reality to a child is *"You know that your brother has been in and out of the hospital because his cancer has been growing. The doctors have done everything they can to make him better but the treatment is no longer working. His body is just too broken and he is going to die soon."*



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After child has received the information that their loved one is going to die, the following are some important choices that can be offered:

- Would the child like to spend some time alone with the person prior to their death to say good bye?
- Does the child want to be present when the person dies?
- Does the child want to continue with their normal routine (i.e., going to school, activities) or would they prefer to remain at home or with their loved one who is dying?
- How does the child want to hear about the death if he or she is not at home/hospital when their person dies?
- Does the child want to see the person after he or she has died? Make sure that children are aware when it is the last time they will see their loved one's body, if possible.
- **Support the child's decision if they change their mind at any time**

The following are some important **school considerations**:

- If a child is at school when the death occurs, how does he or she want to find out that the loved has died? Examples: Be picked up immediately; wait until they arrive home by their normal mode of transportation.
- Who, if anyone, does the child want to tell at school about what is happening? A teacher, counselor, etc. It is **IMPORTANT** to consult with each child in the family about his/her wishes before sharing **ANY** private information with school staff or other families.
- It is not unusual for a child to desire that no one at school be told what is happening.
- It is not unusual for child to desire to be at school on the day of death or immediately following death.
- A social worker or counselor may offer to be a liaison/educator between the school and family.

Our hope is that this article will have strengthened the professional's knowledge base necessary to meet the needs of grieving children. We acknowledge that there is no right or wrong way to be supportive as all children are unique and have an intrinsic strength to be able to cope with the hard things in their lives. With that being said, we hope the considerations offered in this article will help you feel more confident in being able to support children through loss. When entering into a relationship with the best of intent and a heightened understanding of the impact of loss in a child's life, we can help children to build a solid framework to assist them in making sense of the difficult experiences throughout their lives.

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**NHPCO's Pediatric Standards:
A Key Step in Advancing Care for America's Children**

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Despite amazing progress in medicine and technology, the unfortunate reality remains that children die. Approximately 53,000 children die each year in the United States and at least 400,000 more live every day with chronic, life-threatening conditions. While these numbers pale in comparison to the number of dying adults, the impact on families and on society is immeasurable.

As noted in "[A Call for Change](#)," the 2001 white paper by the Children's Project on Palliative/Hospice Services (ChiPPS): "Chronic illness and death can result in devastating consequences for affected children and the people who know and love them, but these consequences are not a foregone conclusion—the harm associated with the death of a child can be lessened by the provision of high-quality palliative and bereavement care."

Currently, only 10 to 20 percent of dying children receive hospice services (generally for a brief duration), and a similar minority of children with life-threatening conditions receive palliative care support and interventions. Barriers to the provision of this necessary care are numerous and daunting. However, the exponential growth in expertise, programs, resources and educational materials—together with the increasing mandate from patients and families, providers, supporters and healthcare monitoring organizations—means that *the time is now* for the field of hospice and palliative care to ensure access to its youngest and most vulnerable members.

The Pediatric Services Survey which NHPCO conducted in 2007 reveals that a majority of responding agencies serve pediatric patients, but only a minority has formal pediatric hospice and palliative care programs with specially-trained staff. Many providers indicate willingness to start or expand pediatric services but lack education, tools, resources and performance improvement methods to create and sustain high-quality programming. In response to this need, NHPCO has developed its first national Pediatric Standards—the "Standards of Practice for Pediatric Hospice and Palliative Care Programs."

These new standards are available online and free to NHPCO members (www.nhpc.org/pediatrics or www.nhpc.org/quality). This article takes a closer look at their development and how they can help advance the quality and availability of care to children.

Developing the Pediatric Standards

In 2006, NHPCO reorganized the Standards of Practice for Hospice Programs (i.e., the "NHPCO Standards") around the "10 Components of Quality in Hospice Care," which serve as the framework for the NHPCO quality initiative, Quality Partners:

1. Patient and Family-Centered Care
2. Ethical Behavior and Consumer Rights
3. Clinical Excellence and Safety
4. Inclusion and Access
5. Organizational Excellence
6. Workforce Excellence
7. Standards
8. Compliance with Laws and Regulations
9. Stewardship and Accountability
10. Performance Measurement



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[Quality Partners](#) has an overall goal of offering user-friendly tools and resources to help NHPCO members demonstrate clear, measurable outcomes for clinical and non-clinical operations and develop a robust quality assessment/performance improvement (QAPI) program. Organizational attention to these 10 domains will not only improve care for patients and families, but will also enable providers to meet the QAPI requirements outlined in the Hospice Conditions of Participation (Hospice CoPs).

The Pediatric Presence

Recognizing the emergence of pediatric palliative care as a burgeoning discipline and the important differences between adult and pediatric palliative/hospice care, NHPCO asked ChiPPS to develop Pediatric Standards. The ChiPPS Quality work group, with members from the U.S. and Canada, took on the task.

While the Pediatric Standards are available as a stand-alone document, they were developed as an appendix or "supplement" to the NHPCO Standards (which is now under development to reflect the new Hospice CoPs). So, the first step was to broaden the language in the NHPCO Standards to include "palliative care," as more children are cared for through palliative care programs than through hospice. The group then spent the next two years developing the new pediatric-specific standards.

Working on the project was an exciting and groundbreaking opportunity for members of the ChiPPS workgroup. As many providers know, the needs of children and their families do not fit into the typical adult hospice model on many levels. Traditionally, hospice programs have cared for small numbers of children, whose needs easily get lost among the large numbers of adults being served in the community. Organizational implementation of the Pediatric Standards will enable the development of safe, effective, high-quality pediatric programming.

Safety is the first and primary goal when delivering care to children and families. Along with safe care, providers must also strive to improve quality by enhancing effectiveness of team expertise in pediatric care. Applying standards and defining best practice allows pediatric hospice and palliative care teams to achieve two major goals: (1) to identify and support specific medical, psychosocial, spiritual, educational, developmental and emotional needs of children of all ages and their families; and (2) to recognize that improvement of knowledge, skills and increased support is necessary for all caregivers. A third benefit of the Pediatric Standards is to allow unmet needs in care delivery to be identified, thus enabling providers to expand services and develop further partnerships with community providers.

Throughout September 2008, the Pediatric Standards were posted on the NHPCO Web site for public comment. The intent of the field review was to give NHPCO members and pediatric hospice/palliative care practitioners the opportunity to review the proposed standards and language, to discuss the document with peers and colleagues, and to provide feedback. After the public comment period, the ChiPPS Quality work group reconvened to incorporate public feedback to strengthen the document. As a result of this process, the Pediatric Standards have evolved to represent a truly democratic and informed pediatric-specific addendum to the adult NHPCO Standards. Hospice and palliative care programs can now use the Pediatric Standards to develop best practices, with the knowledge that the guidelines have been developed, reviewed, and revised by experts in the field of pediatric palliative and hospice care.

Implementing the Standards

The Pediatric Standards do not stand alone, but are designed *to supplement* the NHPCO Standards and set clinical and organizational precedence for hospice and palliative care programs providing care to infants, children, adolescents, and their families in the home, hospital, and long-term care and respite facilities.

As with the NHPCO Standards, successful implementation of the Pediatric Standards involves systematic, intentional application of each of the 10 domains outlined, from Patient and Family-Centered Care to Performance Measurement. The first step is to use the standards as an organizational self-assessment tool. This year, the Pediatric Standards will be incorporated into the Quality Partners Self-Assessment System. The system is currently available for use with the existing NHPCO Standards and provides members with a user-friendly means of assessing their organizations and identifying strengths and opportunities for improvement.



Programs will have the ability to use the same system and principles for the Pediatric Standards when they are added. (To learn more about the self-assessments, visit www.nhpco.org/quality).

Setting the Bar and Moving Forward

All children with life-threatening conditions deserve excellent pediatric palliative care, either as the primary plan of care or concurrently with life-prolonging therapies. In fact, the sole criterion for entry into a pediatric palliative care or hospice program should be that a child is not expected to survive to adulthood. Delays in the inclusion of palliative care strategies and services are associated with increased physical, emotional and spiritual suffering of children and their families.

Families in every area of the country should have access to high-quality pediatric hospice and/or palliative care services, and should have a choice to bring their children home to die when that is the likely outcome. Hospices and palliative care programs are in the best position to provide this crucial care, as they are available in the communities that children call home, and are staffed by interdisciplinary teams capable of alleviating all sources of suffering encountered by children and families facing life-threatening illness.

Creation of excellent, sustainable, robust pediatric services requires each organization to develop a system-wide infrastructure for pediatrics, whether the organization cares for many children or for the occasional child in their service area. Individual organizations will vary in availability of resources to provide safe and effective pediatric palliative care, and may need to partner with programs in the community, regionally or nationally through distance mentoring. Whatever the model, the Pediatric Standards can be used to create a template to prescribe organizational best practice in safe, effective, high-quality care for children and their families facing life-threatening illness.

Thank You!

Development of the Pediatric Standards was made possible through the efforts of the National Hospice Foundation and generous gifts from:

- James R. Borynack
- Brickson Diamond
 - Rita Stein
 - Judith Korn
- Buddy and Nava Korn
- The Mary and Emanuel Rosenfeld Foundation

Resources:

More information on pediatric hospice and palliative care can be found on the ChiPPS web page of the NHPCO Web site (www.nhpco.org/pediatrics). In addition, the following resources are available for purchase from NHPCO's Marketplace (www.nhpco.org/marketplace) at member-discounted rates:

- *Education and Training Curriculum for Pediatric Palliative Care* (Item 820285)
- *Compendium of Pediatric Palliative Care* (Item 810030)
- *Caring for Kids: How to Develop a Home-Based Support Program* (Item 820577)
- Family Education Brochures (available in English and Spanish):
- *When Your Child is in Pain* (Item 821104)
- *Talking with Your Child about His/Her Illness* (Item 821106)
- *Talking to Your Child's Doctor* (Item 821108)
- *When a Child Dies: A Guide for Family and Friends* (Item 821110)
- *Helping Children Cope with the Death of a Loved One* (Item 820974)

NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America

To complement the new Standards, NHPCO has also produced the 11-page report, [NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America](http://www.nhpco.org/pediatrics). This report can help providers—as well as policymakers, funders and the media—to better understand both the current challenges and the unmet needs of children and their families across the country. Visit www.nhpco.org/pediatrics to learn more and download the PDF.

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Items of Interest:

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

- 1. 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, sibling bereavement, self care, ill and dying teens, perinatal loss, neonatal loss, spirituality, unsung heroes in the circle of care, and pain and symptom management for children with life-threatening illnesses and their families. (Please note that you can visit archived issues of this newsletter at www.nhpc.org/pediatrics.) For future issues, we are thinking about addressing subjects such as how to overcome barriers to pediatric palliative care and making memories or legacy building. 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 torkc@sbcglobal.net; Maureen Horgan at maureen.horgan@providence.org; or Chuck Corr at charlescorr@mindspring.com. We will work with you!
- 2. Standards of Practice for Pediatric Palliative Care and Hospice.** Many of the providers which completed NHPCO's Pediatric Service Survey in 2007 had indicated a willingness to start or expand pediatric services, but lacked education, resources and performance improvement methods to create and sustain high-quality programming. ChiPPS created NHPCO's "Standards of Practice for Pediatric Palliative Care and Hospice" (see p. 37).

To complement the new Standards, NHPCO has also produced the 11-page report, "NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America." This report can help providers—as well as policymakers, funders and the media—to better understand both the current challenges and the unmet needs of children and their families across the country.

Members can download copies of both the Standards and the report, free of charge, from the NHPCO Web site at www.nhpc.org/pediatrics. The Standards can also be purchased from NHPCO's Marketplace www.nhpc.org/marketplace (Standards: Item 821399; member price: \$34.99).

- 3. Pediatric Intensive at NHPCO's Clinical Team Conference.** Care for children in the last year(s) of life is an expanding and evolving challenge for providers, regulators and advocates. In 2009 NHPCO's Children's Project on Palliative /Hospice Services (ChiPPS) published the first standards of care for hospices and palliative care providers offering specific guidance on how to optimally care for children and their family members. ChiPPS is proud to be part of creating a Pediatric Intensive to be part of NHPCO's 10th Clinical Team Conference.

The Pediatric Intensive will offer sessions that enhance provider and professional capacity to meet and exceed these standards and ensure that staff have the education needed to confidently care for seriously ill children and their family caregivers. The ChiPPS resources will be featured in the NHPCO Pavilion in the exhibit hall. The Clinical Team Conference is September 24 – 26, 2009 in Denver, Colorado. The Pediatric Intensive kicks off with a full-day preconference seminar followed by a complete track of sessions. For more information visit the Clinical Team Conference Web page at www.nhpc.org/ctc2009.

- 4. Pediatric Palliative Care at Clinical Team Conference.** ChiPPS is proud to be part of creating a Pediatric Intensive to be part of 10th Clinical Team Conference, Facility-Based Hospice Forum, Scientific Symposium and Pediatric Intensive; September 24-26, 2009 at the Hyatt Regency Denver; Denver, CO. Please check the NHPCO Web site for more information and the opportunity to submit abstracts/proposals to future conferences.



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- 5. Support Partnering for Children/Wear a Bracelet.** Partnering for Children (www.partneringforchildren.org) is a national awareness campaign that was launched November 2007 at NHPCO's Clinical Team Conference. The goal of Partnering for Children is to help get the word out about compassionate, family-centered healthcare for children with life-threatening conditions. The ChiPPS work group and the resources ChiPPS makes available is an important part of this campaign. In the memory of the many children whose wisdom and courage inspire us, inspirational bracelets developed by [Children's Hospice and Palliative Care Coalition](http://www.childrenshospiceandpalliativecarecoalition.org) are now available through Partnering for Children. These inspirational bracelets which bear poignant messages from children can be ordered directly online at partneringforchildren.org or by calling 800/646-6460. One hundred percent of the net proceeds of these bracelets go directly to improving care and quality of life for children with life-threatening conditions.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work. If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to CHIPPS2@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the **Communications Preferences** tab in your individual member record online and "opt-in" for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 1-800-646-6460. Visit the ChiPPS Web page at www.nhpco.org/pediatrics for further materials and resources of interest.

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