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Issue Topic: Communicating with Children and Parents

Welcome to the 44th issue of the ChiPPS E-Journal. This issue of our E-Journal offers a collection of articles that explore selected issues in communicating with children and parents. These articles offer suggestions for and examples of engaging in this important aspect of providing pediatric palliative/hospice care. We appreciate that a single issue on this subject will not do complete justice to this very broad subject area, but we hope that the articles in this issue will spur increased awareness and discussion of this subject and we note that all communication is a cooperative enterprise with children, adolescents, their family members, the professionals, the volunteers, and the organizations involved in their care. We welcome communications from anyone who has more to offer on these subjects.

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

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

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Issue #44:
Communicating with Children and Parents
(Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.)

“I Stink”  
Scott Newport
In place of the poems that Scott frequently contributes to our E-Journal, this article describes his efforts in helping mentor new parents of terminally-ill children. Specifically, this article encourages medical staff not to be afraid to speak directly to such parents about difficult topics.

Tell Me about Your Journey  
Christina L. McDaniel, RN, MSN, CHPPN
In this article, healthcare professionals are encouraged “to find the time…find the space…invest in effective communication. Allow your patients and families the freedom to tell their story and be prepared to be present to sit in this sacred space with them. It’s not always about our words.”

Seeing Advance Care Planning as Anticipatory Guidance: A Response to the Seeming Burden of Advance Directives for Infants, Children, and Families  
Melody Hellsten, DNP, Patrick Jones, MD, MA, & Brian Carter, MD
The authors of this article point out that long-standing practices and “tools of anticipatory guidance – relational communication, emotional presence/empathy, and recognition of changes in a child or family’s condition – inform the provision of excellent pediatric palliative care” and can be the basis for addressing needs for advance care planning.

Disclosure  
Suzanne S. Toce, MD
While acknowledging that “there are many barriers to disclosure of impending death to children,” the author of this article argues that “disclosure [of bad news] supports hope, emotional adjustment, full participation in decision making, and advance care planning and should be standard of care.” Some strategies for disclosure are indicated.

Having the Conversation with Your Child  
By Paula, Lydia’s mother
Lydia was 7½ years old when she was diagnosed with Rhabdomyosarcoma. Her mother reports that “The last thing I wanted to do was speak of death and dying to Lydia.” A year and a half later, Lydia herself brought up the topic and they did speak. Her mother writes that “The conversations we had were painful. Not having those conversations would have proved more painful. Nothing was left unsaid. We were able to comfort one another as death approached. Letting Lydia speak freely of dying and answering her questions brought us both peace, and eventually, acceptance.”

Vicki Xafis, PhD, and Dominic Wilkinson, MD, FRACP, FRCPCH
This article describes the rationale for and the contents of “a short hardcopy handbook and a more detailed online resource designed specifically to help parents facing decisions about withdrawal or withholding of treatment for their child.” The entire open access document is available at www.rch.org.au/caringdecisions

Navigating Communication about Death and Dying in the Pediatric Setting  
Dana Dombrowski, MSW, LSW, and Kelly Gross, CCLS, CTRS
On the basis of a thorough grief assessment and an appreciation of a child’s developmental capacities, this article outlines strategies for conversations with a child about death and identifies some resources and tools to support those interactions.
Communicating with a Child Experiencing the Death of a Loved One:
Developmental Considerations
Marilyn A. Fisher, MD, MS
“Open communication within the family regarding the death is crucial if healing is to occur. When children do not feel free to express their feelings or to talk about the deceased, they will feel unsupported and alone in their grief, and may suffer for years to come. When the family is unable to provide the support necessary to support grieving surviving siblings, there is a role for professional assistance.” Such assistance should be based on the developmental considerations outlined here.

You Can Do This: A Parent’s Guide to Helping Siblings Cope with Life-Threatening Illness
Nancy Frumer-Styron, PsyD, with tips from fellow Parents
This article, reprinted from the Courageous Parents Network, offers advice to parents as to how they can help siblings of a child with a life-threatening illness cope. Some tips from parents are included.

“How Do I Tell the Kids?”: Help for Parents Talking to Their Kids about a Cancer Diagnosis
Ann Fitzsimons, BS, MBA
Here the situation is a bit different: how to talk to children when it is a parent who has a diagnosis of a life-threatening illness. An example is given from “a bi-monthly developmentally-appropriate ‘Come and Visit’ tour of the Cancer Center for the children aged 5-12 of adult patients, and their caregivers,” part of the Families Facing Cancer program at the University of Michigan’s Comprehensive Cancer.

Readers’ Corner
- “Talking about Death with Children Who Have Severe Malignant Disease”
  This brief Readers’ Corner piece summarizes a classic article describing research done in Sweden that concluded “Parents who sense that their child is aware of his or her imminent death more often later regret not having talked with their child than do parents who do not sense this awareness in their child; overall, no parent in this cohort later regretted having talked with his or her child about death.”

- “Conversations Matter” from NIH: National Institute of Nursing Research
  This brief Readers’ Corner piece describes useful materials available online from the National Institute of Nursing Research’s project, Palliative Care: Conversations Matter.

Supporting Pediatric Hospice
Sarah Meltzer, MPA CFRE
As Vice President of Philanthropy for National Hospice Foundation, Sarah Meltzer introduces readers to NHF’s fundraising efforts that support pediatric hospice and palliative care.

Items of Interest
In each issue of our ChiPPS e-newsletter, we offer additional items of interest. If there is something you might like to share, please e-mail Christy Torkildson at christytork@gmail.com for consideration.
ADDITIONAL NOTES

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.

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

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

Visit the ChiPPS Web page at www.nhpco.org/pediatrics for previous issues of this E-Journal, additional materials, and other resources of interest.
“I STINK”

By Scott Newport
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“Scott and Penni, I know this is hard and it stinks even having to say this, but Evan may not make it to his first birthday. You guys may want to think about getting a burial site for him.”

The doctor who told us that many years ago was in his second year as a fellow, training to be an Intensivist in a children’s hospital. He was partially correct. We did bury Evan, but it wasn’t till he lived seven, pretty happy years.

Last week I was reminded again of that comment the doctor made and how much it did really stink, especially when having to tell two stinking parents. Even though Evan is gone he left me a gift, sort of a legacy. I now help mentor new parents of terminally-ill children. I also engage medical staff and faculty on strategies in working with these families.

That afternoon last week I was given a referral to a new family and about to leave the hospital when I heard, “Scott, I just finished a twenty-four-hour shift and have been up all night. I really smell!”

“That’s ok,” I said coaching the voice closer, “I still want a hug.”

“Ok then,” she shrugged, “It’ll have to be a proper one then.”

As Carolyn drifted closer, she had to weave past other staff filling the sterile hallway. As she turned to lay her charts on the Formica counter my eyes wandered along the opposite wall. The wall is a sprawling mural of glowing children. It’s named the “Wall of courage.” Evan’s photo is placed right in the middle.

Just beyond the mural was a cracked door; couldn’t have been more than ten steps behind her. Inside the room I could partially see empty twin-sized beds and white sheets still crisp. I think it’s identified as the, “Call room.” I guess Carolyn had never made it there that night while taking care of her sick kids.

Carolyn is a spunky, young doctor at C. S. Mott Children’s hospital at the University of Michigan. She is starting her second year of a fellowship in the intensive care unit. We met last year in July and attended a “Boot camp” facilitated by attending physician, Dr. Tim Cornell, for new hires. I represented the patient and family side of medicine in a high stress, pediatric intensive care environment in these educational formats. The fellowship is for the best of the best doctors in the country who have already completed their residency training in pediatrics and are pursuing a subspecialty in critical care.

After our embrace we both stood there for a moment and just smiled.

“Hey Carolyn, was there one thing that you put into practice after last year’s two-day boot camp training that has impacted the way you do medicine?”

Carolyn didn’t hesitate and said, “Yes there is. When you guys came to talk to us doctors it gave me a sense that I may not have to be afraid to talk to parents with critically-ill kids.”

Before she could say another word, a nurse who had been obviously listening into our conversation at the check-in desk came even closer and seemed to be leaning in to hear the latest gossip on the floor.

Carolyn then continued, “When I go into talk to parents about bad news now, I’m more confident. I have also become aware many of the families already know what I am going to say.”
After saying goodbye I walked past the same conference room we had our conversation a year ago. Reflecting back I couldn’t help but remember her glowing face at the table that day. I know from experience many of the new doctors have two fears. One is how to give bad news and the other is to find a way to offer hope in dire situations.

Well, after talking to Carolyn I know she’s got the first one down and I bet if I ask her the next time we pass, about the hope, she’ll have an encouraging answer too.

Before I went to bed that night I reflected on the trainings I’m invited to do with nurses, medical students, and even first-years fellows like Carolyn. You see, I’m just a carpenter and never had a higher education. My hands are callused and often have unrecoverable stains under my finger nails. I often wonder if the work I’m doing with these highly intelligent folks stinks to them.

Well, at least with Carolyn, if I did stink last year she never noticed. And while she gave me, “A proper hug,” I never noticed her smell either. And maybe, just maybe, that nurse who was listening got a bit of inspiration and training from two stinky people and I’m ok with that.

Now reminiscing back to when that second year fellow fourteen years ago and wondering if that was the best way to say my son was going to die was the best approach. It did stink but it was one of the most special moments in our journey because I know he really cared. I also know second year fellow Dr. Carolyn Vitale cares too, a hope that will last a lifetime and will surely be a sweet aroma passed down to those who will one day train under her passion. Yes, and for all the sick kids and families at C.S. Mott Children’s hospital, families just like mine.

Photo of Dr. Carolyn and Scott Newport.

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TELL ME ABOUT YOUR JOURNEY

Christina L McDaniel, RN, MSN, CHPPN
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I have been blessed in my professional career to be present in sacred spaces with families and patients during what would prove to be some of their most difficult days in a journey they didn’t get to choose. I have laughed and cried, rejoiced and mourned, all in all just been present. One overwhelming piece of knowledge I have gained in all of these humbling experiences is that I don’t have to use all of the words. I don’t have to fill these spaces with words…sometimes (most times) presence is enough. As a health care provider I often got caught up in thinking that I had to have the answers. I felt I needed to be able to communicate through words the support I longed to offer. What I have been taught through these experiences is that this isn’t always necessary.

We put a lot of pressure on ourselves as health care providers to always have the right words. We have to get into the mindset where there is an understanding that there aren’t always going to be the right words available. There are times in our careers that the situations will call for presence and support and not answers or words. In pediatric palliative and hospice care this is truly what we cultivate as a health care delivery model. Our skill has to be in delivering difficult communication while continuing to foster an environment of support and hope. We don’t own or control our patient’s or families’ hope, but we can certainly foster an environment that doesn’t downplay the importance of the psychosocial component of what they are experiencing. Telling their story is important in so many areas of the trajectory of this journey.

There are times though that using words is necessary. Finding a comfort level with conducting these difficult conversations takes experience and training. Understanding how and when communication is appropriate is key to the success of the communication. Physician Diane Meier (2014), Director of the Center to Advance Palliative Care (CAPC), urges that difficult conversations should be approached in a procedural manner with proper forethought and training. This isn't discounting the emotional side of these conversations, but emphasizes the importance of preparation. We have to understand that these conversations take practice and a skill set that has to be developed and mentored. We owe it to our patients and families to take the time to do the training necessary to ensure effective communication around difficult conversations. Dr. Meier’s CAPC video, “The Human Connection to Palliative Care: Ten steps for what to say and do,” (2014) literally walks these type of conversations out in a step by step manner illustrating the importance of proper preparation. When it is necessary to use more than your presence and have verbal conversations around difficult decisions this process is vital.

One of the most powerful statements I have ever used during difficult introductory conversations with my patients and families is, “Tell me about your journey.” This opens so many doors into the needs and desires these patients and families are experiencing. I emphasize that I can read the medical history easily from the chart, but what I want to know more than anything is what they know, where they are, and where they hope to be. What does suffering look like to them? What is the most important thing to them outside of a cure? Allowing for the time and space for this conversation early on will have an exponential return when conversations are getting increasingly difficult. Providing this space gives families the knowledge that their words are just as, if not more, important than the words that we throw at them on a daily basis. This confidence in how important they are to the team builds a trust and collaboration that will be unparalleled.

So the challenge is to find the time…find the space…invest in effective communication. Allow your patients and families the freedom to tell their story and be prepared to be present to sit in this sacred space with them. It’s not always about our words.

SEEING ADVANCE CARE PLANNING AS ANTICIPATORY GUIDANCE:
A RESPONSE TO THE SEEMING BURDEN OF ADVANCE DIRECTIVES FOR INFANTS, CHILDREN, AND FAMILIES.

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Abstract:
Many families affected by childhood cancer, HIV/AIDS, birth defects, neurodegenerative disorders, and a number of conditions that may stem from the perinatal period stand to benefit from receiving anticipatory guidance about what to expect now that they are contending with a life-limiting circumstance. Pediatric providers, familiar with the provision of anticipatory guidance in its developmental role, may be well equipped to employ this strategy as a means to address advance care planning with this unique group of children and their families.

Introduction

Advance care planning (ACP): the process of communicating preferences for future medical care that is consistent with a patient’s values and wishes in the event of a terminal or irreversible condition; typically employed with adults under circumstances of chronic or debilitating illness and in anticipation of death.

Anticipatory guidance: a proactive counseling technique classically employed by pediatricians in addressing child development that focuses on the needs of the growing child at different stages of his/her life.

In the past 50 years, advances in medical technology as well as improved chronic disease management, have led to life extension in diseases that historically would have been more rapidly fatal. Highly publicized, landmark cases in the early 1970s made public the medical possibility of sustaining life, and the subsequent concern for prolonged suffering, in persons who were unable to provide direction regarding their care due to cognitive incapacity. Advance care planning, originally referred to as a living will, was introduced as a means for competent adults to declare their wishes for medical care in advance should they become unable to communicate their wishes at the time of a significant health crisis (Sabatino, 2010).

When children face a high probability of severe illness, disability, incapacity, or death, it is their parents who are placed in the position of determining what is best for their child based on that particular family’s values regarding quality of life, suffering, and death. As such, families need to be engaged in shared decision-making (Nelson, et al., 2003) that is goal determinative. However, goals are not always enduring, or static, they change with the course/trajectory of the illness and particular child’s responses to treatments. As individual children’s lives unfold over the course of their illness, goals need to be revisited and decisions be re-examined. Guidance towards “what to expect” in a disease or treatment path may be very much akin to what general pediatric clinicians recognize as anticipatory guidance. This dynamic process regularly revisits progress, successes and challenges, values, and a reorientation to old and potentially new goals in caring for a child and family dealing with a life-limiting condition. Pediatric clinicians are generally adept at this process – especially in addressing child development – and can easily adapt it to life-threatening or complex-chronic conditions.
What distinguishes anticipatory guidance from advance care planning?

Advance care planning is a process outlined by legal statutes, which vary considerably across the country (Sabatino, 2010). In particular, advance care planning involves the discussion of certain documents, including legal declarations such as directives to physicians for life-sustaining treatments. While ACP documents provide health care professionals with direction regarding general medical interventions that an individual wants and does not want in the event of a terminal or irreversible condition, they often are not easily interpreted by surrogate decision-makers or health care providers in the context of a fluid, dynamic medical event, prevailing medical standards of care, and prognostic uncertainty.

It is important to remember that a signed piece of paper is not the most important outcome of advance care planning. Nonetheless, in practice, the reality of “securing the DNR” or attaining an agreement for limiting or not escalating care is an often-pursued objective in palliative care consultation with families and care teams. But, it is the communication between the patient/parent and clinician that is key.

Anticipatory guidance is a relationship-based approach to caring for children that places emphasis on the expertise of the health care provider caring for children with complex health care needs to create a partnership with parents and children through an illness process. Delivered by a trusted health care provider who is familiar with the child and family, anticipatory guidance lays the foundation for exploring parent, and when possible, the child’s preferences for their care as their condition changes and using that information to shape advance care planning over the course of the child’s care. In this manner, anticipatory guidance is a necessary precursor to ACP.

An important step in anticipatory guidance is the process of eliciting and understanding the patient/parent’s values and life purpose. These are then generally incorporated into some form of goals that orient care towards accomplishing what is of foremost value to the patient/family – that honors the individual child, and both retains past meaning and helps to build new meaning for the patient and family. This process is best illustrated when caregivers take the time to inquire about the individual and become empathetic in their creating opportunities for memories and legacy building for the family. Those actions that are congruent with the identity of the child and the values s/he held – or are voiced by his/her parents – are readily accepted and viewed as honorable by families during times of health and amid crisis.

While providing such guidance in life-limiting conditions may be complicated and emotion-laden, planning for contingencies in times of declining health, or end-of-life care, ahead of time is believed to be of help should the events actually happen. But this cannot be a single conversation. Families often report feeling ‘numb’ or immobile upon first receipt of a life-changing diagnosis. Serial conversations – even redundancy – are in order. The clinician should be sensitive to individual patient and family responses to such conversations and respond in a nuanced manner, appreciative of how a process of advance care planning may seem too demand too much – sometimes even more than might be fathomable for many individuals.

“everyone in the room was looking at me and expecting me to say something – but right then, I couldn’t, I didn’t even know what to do with the news I just received, let alone think about what I would want for her if something else happened.”

What do parents tell us?

The tools of anticipatory guidance – relational communication, emotional presence/empathy, and recognition of changes in a child or family’s condition – inform the provision of excellent pediatric palliative care. They also guide the content and process of individual/family meetings to assure an understanding of a child’s condition. Parents of children in crisis tell us that their strongest desires are to be present, be respected, be engaged and informed in decision-making, and be assured that they are ‘good parents’ (October, et al., 2014). As such, they are allowed and encouraged to reaffirm that their child feels loved, and they are welcomed in advocating for their child’s needs and best interests. Parents prefer
collaboration and partnership with the health care team, as well as recognition that they (parents) know their child best.

**For which children and families might this approach be considered?**

*Anticipatory guidance* has a role in the care of children with a wide variety of complex chronic medical conditions, and it can be useful when a previously healthy child experiences life-threatening trauma or an acute, overwhelming illness. In the case of a complex, chronically-ill child, both the child and family benefit from a primary provider who is able to provide ongoing guidance and address child and family stress throughout the course of an illness. This provider can help bring resources to bear that may maximize the child’s functional and developmental capabilities within their particular condition/illness, as well as attend to the child and family’s quality of life, provide periodic discussion of anticipated changes in the given condition and any attendant risks/benefits of various medical interventions that may be considered throughout the illness trajectory. S/he can help to coordinate care across subspecialty clinics and care settings (home, school, hospital). This process most resembles the anticipatory guidance provided during well child care, and occurs both episodically and more intensively during times of acute illness and hospitalization.

Families who find their otherwise healthy child thrust into a critical, life-threatening situation will require more intensive guidance around the particular circumstances of the child’s condition and what is being done to help the child. In critical care situations, the inherent discontinuity in shift coverage and parent availability creates significant threats to communication around changes in condition and goals of care (Gillis & Tobin, 2011). Rapidly changing and inconsistent information is overwhelming for families and may require identifying a lead intensive care provider to function as the primary person for communicating changes over time. S/he can coordinate information, assist parents in decision making as the process unfolds, and prepare the family for the potential outcomes as they become clearer over time. In concert with palliative care clinicians s/he can assist in transition to either limitation of non-beneficial medical interventions where death is imminent or to a potentially altered level of health status of the child in a new paradigm of chronic supportive disease management and even outpatient palliative care.

**How certain must the clinician need to be in prognosticating?**

One of the most common limitations on advance care planning is prognostic uncertainty. Anticipatory guidance for children with life-threatening or limiting conditions can provide a safe space for uncertainty and allow providers to share information about the child’s condition, discuss potential risks/benefits associated with treatments in the context of the child and family’s preferences, values and beliefs, and promote incremental decision making based on changes over time. In the end, it is the best clinical judgment that prevails, as in pediatric care generally – and perhaps pediatric palliative care specifically – absolute certainty in outcomes is elusive. Yet being prepared, informed, and supported can make these critical and uncertain times bearable (Gillis & Tobin, 2011) for the family and provider alike.

**References & Suggested Reading:**


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DISCLOSURE:

To tell or not to tell, that is the question: Whether 'tis nobler to boldly be truthful to the child about death or avoid the stress of giving bad news....
(with apologies to Shakespeare)

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Open and honest communication about disease and prognosis is an essential aspect of pediatric palliative care. But it isn’t easy. In this article, the main focus is disclosure by the health care provider and/or parent to the child/adolescent patient of poor prognosis including imminent death.

There are many barriers to disclosure of impending death to children. For health care providers, it can be a stressful, uncomfortable conversation. Most providers are not adequately trained in participating in such discussions. They may perceive that parents are “not ready” or had unrealistic expectations of prognosis. (I wonder how often it is that the provider is “not ready”...) They and the parents may feel that they will cause the child anxiety or take away hope. They may perceive that the child can’t comprehend or doesn’t want to know the truth. It can also be a cultural landmine. In many cultures, such as China, it is highly taboo to speak of a patient’s impending death in his or her presence. Speaking of death is perceived as if one were wishing it. Even in the US, the infectious danger of “negativity” is a powerful cultural force. These barriers may lead to conversations that happen very late in the child’s course or not at all.

But, do children know that they are dying? Of course, the concept of death changes with the child’s development, but children with complex medical conditions have advanced emotional and cognitive maturation. Even very young children generally sense that they are dying. Without disclosure, the child senses that those around him or her are insincere. Such children feel isolated and abandoned by those they most care about and depend on.

“Optimism is a good characteristic, but if carried to an excess, it becomes foolishness.”

– Theodore Roosevelt
What is the impact of disclosure of bad news on adult and child patients? Strangely enough, disclosure has been shown to support hope in adult and child patients and in parents. Physician honesty about poor prognosis helped them feel more hopeful. The child can develop alternative hopes such as for a fulfilled life and a good death. Uncertainty of prognosis on the other hand resulted in less hope. Rather than causing emotional harm, discussion about poor prognosis in adults may have psychological benefits with less depression and worry. The child will have less anxiety and can feel a sense of control. Disclosure enhances long-term emotional and social adjustment. Children want accurate information about diagnosis, treatment, and prognosis. They appreciate follow up and ongoing discussion. While they respect their parents, they want full participation in end-of-life decision-making. A child cannot participate in health care decisions if he or she is not told of their disease state and prognosis. With the knowledge gained, the child/adolescent can better participate in decisions and in advance care planning. Without disclosure, a child may be deprived of the opportunity to make his or her death, and life, meaningful. From the parents’ viewpoint, data from a 2004 study showed that no parents regretted disclosing imminent death to their child/adolescent whereas 1/3-1/2 of parents not disclosing regretted their decision. Receiving (and giving) bad news remains distressing, but it is better than the alternative.

What if parents demand that the child not be told of the likelihood of imminent death? Honesty is central to medical professionalism and a cornerstone of pediatric palliative care. Addressing this “honesty” policy with families and children/adolescents should be part of the introductory discussion. While a health care professional may reluctantly agree to a parent’s request/demand not to voluntarily disclose poor prognosis or imminent death, such a professional should respond honestly to a child’s direct question. Communicating bad news is a skill that can be learned. Pediatric palliative care professionals generally are very skilled in communicating with parents and children. When a palliative care team is involved, there is more frequently a discussion of death and dying with the parents and with the child, and there is more likely provision of guidance to parents about discussion with the child (Kassam, 2015).

Some of the strategies used in discussing disclosure with families include (Friebert, 2010; Jamsell, 2015; Mack, 2014):

- Emphasizing that disclosure is a process
- Establishing a culture of openness and honesty
- Beginning the conversation early in the course of a life threatening illness or condition – “hope for the best and plan for the worst”
- Partnering with parents to find hopes and solutions
- Informing parents that you will not lie
- Discussing benefits and harms of disclosure
- Exploring family fears about disclosure
- Involving team members and family supporters
- Encouraging the family to adapt the conversation to the child’s developmental understanding of death
- Responding to the child’s initiative
- Exploring what the child already knows
- Using fairy tales, books, movies; talking about friends and families who had died; talking about life after death; preparing for death through practical preparations
- Employing nonverbal means as needed such as gestures, drawings, play
- Meeting between health care providers and parents followed by meeting between parents and child (option preferred by many parents)
- Accepting that some children do not want to hear bad news and will manage to avoid it
Disclosure of a poor prognosis including imminent death is a distressing process for all participants. However, disclosure supports hope, emotional adjustment, full participation in decision making, and advance care planning and should be standard of care.

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HAVING THE CONVERSATION WITH YOUR CHILD

By Paula, Lydia’s mother
September 18, 2015

My daughter, Lydia, had been diagnosed with Rhabdomyosarcoma when she was seven-and-a-half years old. In spite of proton therapy and protocol after protocol of various chemotherapies, the inoperable tumor behind her jaw kept growing.

The last thing I wanted to do was speak of death and dying to Lydia. I wanted to maintain a positive attitude and keep hope alive. I wanted to keep Lydia alive.

Lydia had battled cancer for almost a year and a half when she broached the subject of death. She was curious. “Mom, if I die now, do you think God would let me see myself as a teenager?”

At that moment I realized Lydia’s need to speak of death had to supersede my fear of her dying.

“I think so.” I answered. “If He could create the world, letting you see yourself as a teenager would be easy.”

Lydia’s courageous inquiry opened the door for a serious conversation. I took the opportunity to ask more questions.

“So, if you die, what do you think you would want?” I ventured. “Would you want to be buried…cremated…?”

Lydia laughed at the idea of cremation and her ashes being kept in an urn. “Oh gross! You wouldn’t want a dead person in your house!” she exclaimed. Her sense of humor lightened the mood. “I’d want to be buried…”

Lydia’s one question began an honest and ongoing dialogue about death. This was greatly encouraged as a healthy way to deal with our circumstances by Lydia’s medical team which included a social worker and palliative care team member.

Lydia and I benefitted from straightforward discussions. We comforted one another while mourning our impending loss. Months after our first conversation, Lydia asked, “Mom, will you be ok if I die?”

“Remember how it was when Grandma died last spring?” I asked. My mother died a year into Lydia’s two-year cancer battle.

“Yes,” she responded.

“I was very sad. Sometimes I still am sad and cry. I miss her every day, and yet I am able to carry on.” Lydia contemplated this as we recalled our own grieving process through my mother’s death.

“If you die, I’ll be heartbroken.” I continued. “But, I know you will be in heaven with God and Grandma. I will cry sometimes, just like I do when I miss Grandma.”

“I don’t want you to be sad,” she said.

“I will have good days too. Just like you and I have good days in spite of Grandma’s death,” I assured her.

As our conversations continued, Lydia and I talked of hopes, dreams, and the afterlife. Before bedtime, we sometimes read the Bible together and found comfort in Corinthians 13:13 “these three remain: faith, hope and love…” We had faith our love would remain, and we hoped for a future together in heaven.
As time passed, Lydia's tumor grew in spite of all medical efforts. Finally, we ended cancer treatment and treated only for comfort. Lydia’s Palliative care team carefully regulated her medication to keep her as pain-free and as alert as possible. They were our liaison with hospice care that did not specialize in Pediatrics.

In late April, 2013, after a five-day hospital stay, we knew the end was near. Lydia adamantly wanted to go home. Following much consideration and discussion with Lydia’s medical team, we brought her home via ambulance.

Two days before Lydia’s last breath, she looked at me and said in a matter-of-fact tone, “Mom, I’m dying.” Our previous conversations had paved the way for her to readily admit it.

In this, our last in-depth discussion, we spoke of Lydia’s brave fight to live by following dauntless protocols of chemotherapy, and by submitting to proton and radiation therapy. Throughout it all we had prayed for a miracle.

“If God wants you now, there is nothing more we can do. We have tried everything,” I said.

I held her small hands in mine and continued, “Time will go quickly for you in heaven, and before you know it, I’ll be with you.”

Looking at Lydia, I saw her nine and a half years flash before me: so much strength, love, courage, intelligence, wit, beauty, and humor. “I’m so proud of you and I will love you forever,” I said and apologized for mistakes I had made as her mother.

She squeezed my hand and said, “I love you Mom. You’re the best mom ever.” I hugged her and she whispered in my ear, “I’ll never forget you.” We held each other.

Watching Lydia’s body deteriorate was torment. However, having Lydia at home was a blessing. It was where she wanted to be. A hospice nurse stopped by once a day and would be there at a moment’s notice if needed.

The night before Lydia died, her breathing was shallow. She struggled to get comfortable. I laid down beside her, held her hand, and we both finally managed to fall asleep around 5 a.m.

Three hours later I awoke, but Lydia slept on, breathing ever so slowly. At 10 a.m. she took her last breath. A moment later, a slight smile formed upon her lips, like a gift of assurance she was happy to leave the pain behind and enter heaven.

Our discussions of death were an amazing help in the end. I was not faced with daunting decisions in the depths of my despair after Lydia died. I did not have to question what my daughter wanted.

She had told me. Lydia did not want to be cremated. She wanted to be buried in a white coffin, with her teddy bear, Milkyway, in the cemetery next to her elementary school. This child who was unable to choose what happened to her body in life because of cancer, was empowered to choose what happened to her body after death.

The conversations we had were painful. *Not having those conversations would have proved more painful.* Nothing was left unsaid. We were able to comfort one another as death approached. Letting Lydia speak freely of dying and answering her questions brought us both peace, and eventually, acceptance.

*Reprinted by permission from Courageous Parents Network ([www.courageousparentsnetwork.org](http://www.courageousparentsnetwork.org)).*
Even though the death of a child is a relatively rare occurrence in developed societies, when it occurs the child’s death is often preceded by an end-of-life decision. In these situations, parents are called upon to make decisions about withdrawing or withholding potentially life-prolonging treatment from their child. Such decisions are devastating for the parents; factors that further complicate making them are parents’ inexperience with the medical context, inability to know what to ask, as well as uncertainty about the right thing to do.

There are limited existing written resources that assist parents in dealing with considerations of this kind and until recently no resources that dealt specifically with some of the key ethical questions that arise in such considerations. The Caring Decisions resources comprise a short hardcopy handbook and a more detailed online resource designed specifically to help parents facing decisions about withdrawal or withholding of treatment for their child [1]. Caring Decisions was developed to fill the gap in existing resources and to provide parents with the language they need to better engage with healthcare professionals in these demanding circumstances. The resources also provide narratives and quotations from parents who have previously experienced end-of-life decisions for their child.

### Topics covered in the parent resource Caring Decisions

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**Disagreement**

What should I do if the doctors don't agree about life support? What should I do if I don't agree with my child's doctors about life support? What should I do if my partner and I do not agree about life support treatment? What should I do if others in my family do not agree about life support treatment?

**Religion, culture, and life support**

Is it against my religion to stop life support? Is it playing God to stop life support? What about the sanctity of life? I don't want to stop life support because I am waiting for a miracle. Can I talk to my doctor about my cultural or religious beliefs? Can I ask doctors to speak to my elder or religious advisor? What do different religions say about stopping life support?

**After a decision**

We have decided to continue life support. What will happen now? We have decided to stop or not start life support. What will happen now? What happens after a breathing tube is removed? If my child has morphine, will it stop him/her breathing? How long do we have? What about organ or tissue donation? What do I do about organising a funeral?

**Taboo questions**

What if I had… If only I had…? Is it bad to wish for my child to die? Can't the doctors give my child something to put them out of their misery? Do doctors want to stop life support for my child because it costs too much? Is stopping life-support treatment giving up on my child? Is there no hope?

The doctors cannot be right. They must have made a mistake. If I agree to stop life support, will people think I am a bad parent? Will we be abandoned? Will I be letting the doctors down if I agree to stopping or not starting life support? What about the rest of my family and their quality of life?

I am afraid that I won't be able to cope if… . 'Did I make the right decision?' Will I be able to live with myself?

**What to tell other people**

Should I say anything? What do I tell other people about life support? What do I tell my other children?

**Further information**

Adapted from [2].

Prior to developing the resources we performed a detailed literature review to ensure that the Caring Decisions resources were evidence-based. The initial intent of the review had been to identify published literature on written materials for parents making end-of-life decisions. Due to the paucity of such publications, however, the search was broadened to identify studies that provided insight into what information parents found helpful and unhelpful when making end-of-life decisions for their child. This literature review subsequently led to a meta-synthesis of parental feedback [3] and provided evidence for the kind of information and presentation of such information that would be useful for parents in the written form.
Features found to be shared by parents who made end-of-life decisions for their child include the following [2]. Parents:

1. want written resources to help them retain information [4, 5].
2. seek information from other sources including the Internet even though they heavily rely on healthcare professionals [6-15].
3. lack scientific knowledge and they may doubt their decisions [16]. Some prefer to leave decision-making to professionals because of their lack of understanding [17-19].
4. do not know what to ask so are sometimes privy to less information [20-22].
5. find medical jargon confusing and overpowering and find it hinders comprehension of information [21-26].
6. would have made different decisions if they had had access to more information [9, 21, 22, 27-29].
7. want information to be delivered in a simple, honest, and compassionate way to reduce their fear, increase their sense of control, and help in decision-making [25, 30-33].
8. believe talking to parents with similar experiences is important, as it is believed to influence decision-making, help parents cope better with their decisions, or prepare them better for future events [34, 35].
9. find that the support (or lack of) from healthcare professionals impacts on the parent-healthcare professional relationship and on decisions, as emotional distress affects decision-making [6-8, 25, 26, 30, 34].
10. find conflicting information from healthcare professionals disturbing and acknowledge the difficulties in relationships that disagreement between parents and clinicians cause [7, 25, 26, 30, 31, 36, 37].
11. want healthcare professionals to tell them about (prognostic/diagnostic) uncertainty and the dilemmas they face [32, 37-39].
12. vary widely in the level of decision-making involvement they prefer: Reluctance to make decisions [19, 40, 41]; Involvement in discussions but not decisions [17, 33]; Shared decision-making [16, 22, 30, 31, 42-47]; Parents’ responsibility [16, 26, 48-51]; Not full responsibility [17, 18, 30, 33, 41-43].
13. try to take into account their child’s quality of life when making end-of-life decisions but find it difficult to determine this [48, 52, 53].

During the development of the Caring Decisions resources, we undertook a consultation phase drawing on experience from a range of experts from Australia and overseas and, importantly, parents who had themselves made end-of-life decisions for their child. The feedback was overwhelmingly positive, but some changes were made based on suggestions provided. We carefully considered whether the information provided in these resources was balanced and reflected on what it means to have balanced information in counselling around end-of-life [54].

Following the development of the Caring Decisions resources, we performed a small pilot evaluation study to test out the usability and appropriateness of the use of the resources in both a neonatal and paediatric intensive care unit in an Australian hospital. This evaluation study revealed that the resources were considered appropriate and very useful for parents but also for healthcare staff who might wish to better understand the issues that parents find important and ways of articulating information in an honest yet sensitive way.

While these resources have been found to be very helpful for parents and clinicians alike, we acknowledge that such materials can never replace the communication that occurs between healthcare professionals and parents. The developers of Caring Decisions hope that these resources will assist in clarifying the language used in the context of life-sustaining treatments, will illuminate the concepts considered in relation to the ethical dimensions of decisions to withdraw and withhold such treatments, and that they will help parents deal with some of the most difficult decisions they will ever have to face.
REFERENCES


Talking about death and dying is difficult, often being described as “the elephant in the room.” Now, think about talking to children about death and dying and how complicated this becomes. Parents and caregivers often avoid this topic as a way to protect their children. We (both caregivers and professionals) worry about saying the “wrong” thing, the difficult and real questions that children ask, and about how to explain what dying means.

To best support children and their families, communication should start with a thorough grief assessment of all family members and a safe space to have open discussion. Grief is the normal and natural reaction to loss and can even be felt in anticipation of a loss. It is the complete range of naturally occurring human emotions (James & Friedman, 2009). We need to recognize that each person’s (both adult and child) grief is unique and their ability to talk about death is different. Think about what other experiences with loss they have had, and the influencing/risk factors (Glass et al., 2006). Each individual and child will be ready for different depths of conversation at different points in time.

The focus of this article will be the strategies of communication about death and dying, but it is imperative to acknowledge that a child’s reaction to conversations surrounding death and dying will correspond with their developmental/cognitive age. Understanding may range from none at all, to belief that death is reversible or magical, to a more complete understanding of the finality that death brings.

Communication Strategies

When broaching the conversation about death and dying with a child, it is important to consider not having a set agenda or focusing too intensely on the medical details. Go slow, and allow for moments of silence. Silence provides an opportunity for a child to process his or her thoughts and feelings and formulate any questions the child may have. If the child asks to go play during the conversation, allow it. This is their way of expressing that they are overwhelmed and need a break. A conversation about death usually doesn’t happen in just one moment of time. It is a series of conversations and shared experiences that take a lot of patience and presence over a course of time.

There are four basic concepts about death that may be important when communicating with children. Death is irreversible, all life functions stop completely at the time of death, everything that is living eventually dies, and there are physical reasons why someone dies (Shonfeld & Quackenbush, 2014). Parents have many times expressed being afraid that talking about death will cause more anxiety or fear. Alternatively, we have found that open, honest, age-appropriate conversation can bring relief to children. Children are observing our behaviors and actions all of the time, even when we think they are sleeping or not paying attention. They have likely already sensed that things are changing, something is happening, or that they (or their sibling) may be dying. Anxiety may actually be reduced when the situation is talked about open and realistically. Sharing emotions gives children reassurance that it’s okay to cry, be scared, and most importantly, be honest with how they are feeling (Goldman, 2009). It is imperative to do this in a sensitive and age-appropriate way.

Prior to talking directly to a child about death, whether it be that of a patient, sibling, or the child involved, it is important to sit down with the parents/caregivers to identify what the child knows about their (or their sibling’s) medical situation. Has the child had any past experiences with death, either that of a friend,
family member, or pet that would help open up the dialogue and bridge their understanding of death? While working with a family who was struggling to explain the impending death of their son to their three-year-old daughter, the three-year-old’s class fish, “Bubbles,” happened to die. This event allowed the parents and professionals to use it as a starting point of conversations regarding death and its process.

Identifying familial beliefs about death and the terminology that would best suit the family is also important. Do they believe in heaven or an afterlife? Do they use the words angel or God? Or, are there no religious affiliations or spiritual beliefs? While working with a family whose ten-year-old son was dying, the parents struggled with how much information to give to his seven- and nine-year-old siblings for fear of causing them anxiety. This particular family did not have any religious affiliations, no beliefs in heaven or an afterlife and believed when you die, it is the end of all life. The mother had contemplated talking about heaven just to have something to say to her children to try to comfort them. With support and guidance from professionals, the parents were able to create a safe space for conversations with their other children and use the terminology they were comfortable with. The children were able to ask their questions and also expressed that they knew something was changing given that both parents remained at the hospital at all times. The parents expressed much relief that they were able to talk about the facts and reality of their situation without having to make something up that they didn’t believe in. Parents expressed some surprise that their children seemed to take comfort in an informed update about their brother even though it was such sad news.

Ask clarifying questions to get to the root of what children are really asking and use direct, simple terms while avoiding euphemisms. Terms we frequently hear about death include “passed away,” “gone to sleep,” or “went to be with God.” To children that aren’t familiar with the concept of death from prior life experiences, this can be confusing. Vague descriptions may lead the child to believe that the deceased person can return at some point or that they will “wake up.” We need to help them understand that death is permanent, that nothing they (or their sibling) did wrong or caused what is happening, and most importantly, that they are loved, cared for, and safe. It may be most important to recognize that we don’t have all of the answers. Give yourself permission to say “I don’t know” or “Let me ask someone that may know or be able to help.”

Tools

There are tools and resources that can be utilized in helping children deal with their grief and understand and talk about death and dying. If you are in a medical setting, consider your, Palliative Care, Child Life, and/or Social Work resources. These are trained individuals that not only have the skills to support and counsel family members, but also are comfortable in talking directly to children. They can provide support and guidance to parents who are having these ongoing discussions directly with their child. Child Life Specialists are also trained to communicate through other modalities including art, play, and education. If not in a medical institution, local resources may include hospice agencies, grief centers, and counseling services.

Resources

https://agingwithdignity.org/shop/product-details/pediatric-my-wishes - My Wishes and Voicing My Choices documents can help to give us the language tools needed to talk to children about end of life, wishes, and goals
www.achildingrief.com
www.childrengrieve.org

References


-###-
Maria's parents were anxiously awaiting the birth of her new little sister. Much preparation had been made in their household as they prepared for the new baby. Maria's bedroom had received a fresh coat of pink paint and her furniture had been re-arranged. Her bed was now pushed against the wall and her bookcase and toy box had been crammed into one half of the room. The other half of Maria's room was now occupied by the crib, the changing table, an extra-large trashcan with a lid, and a bunch of bags and boxes. Juvenile decals of hot pink giraffes and lemon yellow hippos were plastered on the wall near the crib. While her parents were thrilled in anticipation of Sofia's arrival, six-year-old Maria was not so sure that this was a good thing. She didn't relish the idea of sharing her room with a baby. She remembered her two-year-old brother Jack crying at all hours of the night when he was a baby. And she remembered the awful, smelly messes he would make, and still makes, in his diaper. And, Jack didn't even have to share a room with Maria. Sure, it might be fun to have a little sister someday, but Maria didn't feel quite ready for this now. On the night her mom and dad had to go to the hospital, Grammy came to stay with Maria and Jack. Grammy gave Maria and Jack their goodnight kisses and said that when they awakened in the morning, they would have a brand new baby sister. But, in the morning, when Maria awakened, Grammy was sitting in the kitchen in her pajamas, hair in a mess, talking on the phone. And crying. Grammy explained to Maria that something was dreadfully wrong with Sofia. That she wouldn't be coming home. That she was going to die. Maria was not sure what that all meant, but she could see that it caused Grammy to be very sad. She felt guilty and ashamed for having thought bad thoughts about Sofia for, surely, her bad thoughts had caused this tragedy. Later, Dad came home to tell Maria more information, and he was crying, too. When Jack saw Grammy and Dad crying, he began to cry, too, without understanding the cause of their sadness. Maria felt guilty and ashamed that her bad thoughts had caused Grammy, Dad, and Jack to cry. She just wanted reassurance that her mom was alright and that, maybe tomorrow, her world could continue on as it had been before. Maria felt guilty and ashamed that she felt a little bit glad that she wouldn't be sharing her room with a noisy, smelly baby. But she kept that thought to herself.

Maria was not allowed to go to the hospital with her parents. Secretly, she imagined that Sofia was a giant monster baby and that it required both mom and dad to change her giant smelly diapers. She hoped that, soon, Mom and Dad wouldn't have to spend every waking moment at the hospital, and that they would have time to play with her. She hated Sofia for taking Mom and Dad away from her.

When Maria awakened the next morning, she was surprised to find that she had wet her bed.

A child’s ability to comprehend death is limited by her neurodevelopmental level. In general, this is dependent upon her age. While neurodevelopmental maturity is a continuum, neurodevelopmental processing of death may be divided into 4 major age categories (Schuurman DL, DeCristofaro J, 1999):

**Up to 3 years.** Children in this age category are egocentric (i.e., they believe that the world revolves around them). They share their stories (with regards to death and other life experiences) with family and
strangers alike, without discretion. They lack the cognitive ability to grasp the abstract concept of the 
“forever-ness” of death and see it as a reversible condition. Even though they may not possess the 
vocabulary necessary to express their grief, children in this age range may exhibit their grief in the form of 
movement and physical activity/play. In their artwork and play, they may demonstrate how they may 
“save” the person who has died. If adults can acknowledge their words and play, the grief-stricken child 
will feel as though she is being heard, understood, and respected. Children in this age category may 
reflect the emotions demonstrated by others without understanding why such emotions exist. For 
instance, in the scenario, Jack began to cry when he saw his Dad and Grammy crying, without, at that 
time, feeling grief or understanding why the others were crying.

4 – 7 years. Children under approximately 8 years of age cannot comprehend the idea of permanent 
death, but they can appreciate the idea of being gone permanently. They may not understand the term 
“death” or “to die.” A concrete definition of death needs to be provided to them. In the scenario, Maria, 
thought that death meant that Sofia would never come home and that her parents would have to spend all 
of their waking hours at the hospital from then on. Maria’s family would have been appropriate in telling 
Maria that a dead person can’t move, have a heartbeat, breathe, play, laugh, eat, pee, poop, sleep, think, 
or anything. Children in this age range try to make sense of the death, try to link cause and effect. Still 
somewhat egocentric, they may exhibit magical thinking, believing that they are somehow responsible 
for the death. Maria believed that her ambivalence towards having Sofia share both her bedroom and her 
parents’ attention was the reason for Sofia’s death. Adults should provide reassurance to the child that 
nothing that they may have thought, said, or done was the cause of the loved one’s death. Children 
should be offered the opportunity to visit/see the dying or deceased person, as their imagination may be 
more than reality. Maria imagined that her sister was a baby monster. Having improved language skills, 
children in this age range may want to ask many questions regarding how and why the death occurred. 
The supportive adult must be available, physically and emotionally, to answer these questions, and to 
welcome even more questions, as well as to discuss feelings about the deceased. Adults must take care 
in their description of how the death occurred; an attempt to reassure a child that the death was painless 
(“Sofia died peacefully in her sleep”) could make the child terrified to go to sleep or to sleep alone, for fear 
that she will die, too. This is why it is important to include sleep in the list of activities that a dead person 
cannot do.

8-11 years. Children in this age range are better able to understand the abstract concept of death. These 
children may worry about their own mortality, or that of other loved ones. They may develop somatic 
symptoms, sometimes reflecting the symptoms of their deceased loved one. These children may also feel 
some sense of responsibility for the death. Their emotions may range from sadness to anger to despair to 
fear to relief. Since they didn’t have a choice about the person dying, they should be offered choices with 
regards to how they wish to express and process their grief. This may involve being offered an informed 
choice about visiting the dying person, or seeing the deceased after death, attending the funeral, etc. 
Photographs or possessions of the deceased may be offered. The child may choose which of these 
mementos is most important to her in supporting her grieving process, and what she will do with these 
items. Children of this age range, and beyond, may keep the spirit of the deceased alive by assuming her 
preferences and manners.

12+ years. Adolescents have a strong connection to their peers and life outside of the home. However, 
none of their peer group is generally able to appreciate the adolescent’s grief at the loss of a sibling. 
Despite feeling alone and unsupported by their peers and, perhaps, unsupported at home as well, 
adolescents, in particular, will make efforts to appear and act normal, and to appear and act no different 
from others of their peer group. Common adolescent emotions in the aftermath of a sibling death include 
anger, depression, anxiety, and guilt. In the aftermath of a sibling death, adolescents report an increased 
level of maturity, improvement in academics, deeper appreciation for life and living life at its fullest, less 
risk-taking, ability to better express affection towards those in their lives, higher moral values, and a 
sense of a greater purpose in life (Balk, 1983; Forward & Garlie, 2003). This tendency towards 
overachieving may be due to a feeling that they are not good enough to make their parents happy again. 
Alternatively, the child may act out in negative ways, seeking proof that her parents still love her. This 
behavior may be precipitated by the grieving parents immortalizing the deceased child.
Because the grieving process is both an individual and a group (family) process, a child's death disrupts the entire family function, alters the way surviving siblings interact with each other and the way surviving siblings interact with their parents, and changes family members' self-expectations as well as expectations that the family has for itself as a unit (Detmer & Lamberti, 1991). A surviving child may feel that her parents are not physically nor emotionally available for her. Thus unsupported in their grief and disconnected from their family, surviving children may feel that they no longer belong to the family. Relationships among siblings are unique because siblings often spend a large part of their lives together. Siblings are friends, confidantes, playmates, role models, and protectors. Siblings use each other as points of influence in defining their own personal identities. Since their histories are often inextricably entwined, with the death of a sibling, the survivors essentially lose a part of themselves (Devita-Raeburn, 2004). After the death of a sibling, survivors often feel an ongoing sense of attachment with their dead sibling (Hogan & DeSantis, 1992). This may include: (1) regretting—desiring to have a better relationship with the deceased, wishing to continue a shared relationship; (2) trying to understand reasons and circumstances for the death; (3) catching-up—depending on religious beliefs, asking what Heaven is like, how are they doing there as if they are still alive, but somewhere else; (4) reaffirming—loving and missing the sibling; (5) influencing—seeking guidance from the sibling, feeling that the sibling is watching over the survivor; 6) reuniting—anticipating reunion in Heaven, depending on religious beliefs. The depth and nature of emotional closeness that existed between siblings prior to the death influence the surviving child’s grief processes (Davies, 1995). In relationships where the sibling relationship was ambivalent or conflictual, or marked by just one-sided ambivalence, as in Maria’s case, the connection to the dead sibling may be disturbing or frightening.

Surviving siblings may express their internal pain in a variety of external ways: crying, withdrawing, regression, attention-seeking (positive and/or negative), psychosomatic complaints, nightmares, fear of going to sleep or of the dark, etc. As the surviving sibling advances to new neurodevelopmental levels, her concrete thinking becomes more abstract. She will need to re-process her old grief with her new neurodevelopmental skills. She will need parental or professional assistance for this (Packman, et al, 2006).

Parents play the major role in assisting grieving siblings to cope and adapt to the loss of a sibling. Sibling loss, however, has been described as a double loss. Surviving siblings, attempting to cope with a sibling’s death, seek support from their parents. However, their parents are generally consumed by their own grief and do not possess the emotional wherewithal to provide support for their grieving children. Grief of the surviving siblings is often unacknowledged, unsupported, and invalidated, as friends and family will hug and offer condolences, time and attention to the parents, but not to the siblings. Parental distress may be so intense that the (also suffering) children will attempt to protect their parents by never mentioning the deceased as they believe it will upset them even more (Horsley & Patterson, 2006).

Open communication within the family regarding the death is crucial if healing is to occur. When children do not feel free to express their feelings or to talk about the deceased, they will feel unsupported and alone in their grief, and may suffer for years to come. When the family is unable to provide the support necessary to support grieving surviving siblings, there is a role for professional assistance.

References:


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YOU CAN DO THIS: A PARENT’S GUIDE TO HELPING SIBLINGS COPE WITH LIFE-THREATENING ILLNESS

Guidance from Nancy Frumer-Styron, Psy.D.
Psychologist and Grief Counselor
Content Director for COURAGOUS PARENTS NETWORK
With tips from fellow Parents

(Adapted from the video interviews available at courageousparentsnetwork.org.)

It’s important to talk from the very beginning about the other children.

The minute one child gets diagnosed, all the focus, all the attention, all the learning ends up on that particular child and on that situation. Sometimes, though never intentional, but almost to the neglect of the other children. Parents become absorbed by the logistics of the sick child’s needs, but need to keep in mind that the other children still have to go to school, still have to get dressed, still have to eat, need to be picked up or need to be taken somewhere. It becomes about figuring out how we’re going attend to the practical pieces and the emotional pieces.

Even though they completely understand that it was not intentional, siblings often report feeling almost abandoned: they felt shuttled from person to person. Yes, there were always caregivers, people to feed them, pick them up, take care of them, help them do their homework, but it wasn’t their parents. They felt pushed aside.

Sometimes, jealousy can arise. Suddenly the sick sibling is getting all kinds of presents and people visiting, and the other children are sort of wondering Why Me.

Sometimes, the siblings are also experiencing some guilt around why this happened to one child and not the other. They may also be experiencing relief, but they don’t want to say that. They’re very worried about burdening their parents with sort of one more thing, so they’re not sharing about what happens.

This can manifest in all kinds of ways: you may have the perfect child in the back of the room because they don’t want to rock the boat. They know the family is already upset, things are already shaky, so they’re going to be super good. And then other times you see the very worried, sometimes acting out child, or the child who has a lot of separation anxiety - may have had it to begin with but maybe not - suddenly doesn’t want the parent to go, is having trouble sleeping or having trouble in school.

We have to keep a developmental frame all this time, so it depends on how old these children are that we’re talking about. It becomes important for parents to recognize that sometimes leaving the hospital while one child’s napping to go and be with the other child at home is really important.

Parents need to own how stretched they feel and even share that with the other children. Tell them how much you love them and that you are going to do the best you can.

You can’t be in two places at one time, and sometimes you will feel guilty about having to attend to the sick child and not being able to be with the other children. It is really important to talk to the children about that, so that they understand that you, their parents, want to be with them as well. Tell them that you are going to do the best you can to divide your time. Tell them that if they were sick, you would be doing this for them too.

Let them know that if there are special things or special events, at least one parent is going to try and be there.
You can model and teach communication skills to your other children.

Tell them that it is their job to let you know when they need something and that you want them to tell you how they are feeling – that is safe for them to do that. And then be sure to check in with them every day, even if it only by phone from the hospital.

If you’re staying at the hospital, make sure you call home to say goodnight or call and say how was school, what did you do today? You can use Skype or FaceTime.

This helps keep the other children in the loop, helping them know what’s going on, so they don’t wonder or worry more than necessary.

Always give them a sense of what’s actually going on and invite them in.

We always want to make sure children have information in age appropriate ways. You don’t have to do this by yourself. You can get help from a psychologist, a social worker or somebody at the hospital to help them know what is actually going on and how they could be part of this too.

Wherever possible, invite your other children to be helpful. Kids like to help. They don’t want to feel excluded, so use the resources that you have at the hospital or the clinic or wherever the treatment is occurring to bring the other children in.

Just an hour in the hospital so they can see can be very helpful: If your child is in the hospital, bring your other children in so they can see what the room looks like, what the playroom looks like, that it’s not a scary place. Excluding them only increases their fantasies about something bad happening.

They’re going to have questions. It’s important not to lie to them.

Depending upon how old they are, your children may ask lots of questions. They may ask a couple of questions and run away and then come back a few days later.

It’s important not to lie to them. Give them short pieces of information. Let them take it and think about it, and if they come back and say “Remember when you said...?” -- now, now they have another question.

It is helpful to prepare yourself for the questions.

Kids can be very bold and far less inhibited than adults, which means they sometimes ask really tough questions right up front, and it can throw you as their parent for a loop when they ask the questions. For example, they hear that their sibling is very sick and in the hospital—the sibling may ask, “Is she going to die?” Depending on the child’s age when they ask this question, they probably aren’t asking if the sister could die, but rather, is she going to die soon (today, this week).

This can be very alarming to hear your child ask and it can be helpful to get a professional – such as a psychologist or social worker – to help you anticipate what some of the hard questions might be. Then you can prepare for how you want to answer them, what you want your child to know. By preparing yourself, you can give answers in a compassionate and kind but confident way, so that it isn’t scary for the child even if it’s difficult information to hear.

Be careful: It’s important to know what the child is really asking. Don’t give them information they haven’t really asked for.

Sometimes, when a child asks “Is she going to die?” what they're really asking is, “Is she going to die today?” and if the answer to that question is pretty clearly No, that’s really actually all they’re asking, and you can answer No.
It is also important to find out what your child thinks and already knows.

Children learn things from all different places and may have a whole lot more knowledge than you think they have. So it’s very important to understand what your children know even if you haven’t been the one to share that information.

Also, if your child has an interesting question about what happens when somebody dies and you have your own very specific thoughts about that, you may end up providing way too much information that is not appropriate for a child who is young.

To deal with this, try answering instead: That’s a great question. What do you think? Then you can learn what your child is really thinking or already knows. They may have an entire framework and an answer for the question. They just needed to ask it to see whether you could tolerate the question.

Your child may also have a misperception or misunderstanding and you can help clear up their confusion, but without giving them a huge explanation that is more than they can handle.

Selected Additional Tips from Parents

Our older children helped give their younger brother his medication.

If we couldn’t answer a question that our sons had about their brother, we asked the child-life specialist to answer it.

We tell our older daughter, age 13, everything about her sister’s condition. We don’t keep anything from her.

I told my son that it was OK to be really sad and cry about his younger sister’s illness. We cried together.

We got our older daughter grief counseling from the very beginning, so she would have someone to talk to, to share her sadness with in case she was trying to protect us.

We had to teach our older daughter’s teachers about the situation at home, so they would know what she was going through at home with her brother.

Sometimes we let other family members stay with our daughter at the hospital, so we could be home with our other children.

Print Your Own Conversation Cards

Print and gift these cards (found on the next page) to your children, giving them an outlet and opportunity to express their thoughts and questions. Be sure to set a time specific time each week to discuss anything your child would like to share from the cards. Setting and sticking to a discussion time will help your child to feel heard and taken care of. These cards can also be used as a tool for a grief counselor or school support person.

Reprinted by permission from Courageous Parents Network (www.courageousparentsnetwork.org).
“HOW DO I TELL THE KIDS?”:
HELP FOR PARENTS TALKING TO THEIR KIDS
ABOUT A CANCER DIAGNOSIS

By Ann Fitzsimons, BS, MBA
Executive Director/Founder, here4U, Inc.
Ann@here4U.net

When a parent receives a cancer diagnosis, one of their first worries is not about themselves, but about their children—no matter how young or old (even into adulthood) they are. How will they tell them? How much should they tell them? What do they tell them? While the parents are struggling to cope with the diagnosis themselves, they’re also wrought with worry and fear about how the kids will take it and cope during what could be a series of potential surgeries, chemotherapies, radiation treatments, medications, side effects, etc., and all that a cancer diagnosis and treatment brings to a family.

In my own family, my sister had a baby “born dying” of a malignant brain tumor that went undiagnosed in utero. She died two weeks after her birth. Five years later, this same sister was diagnosed with cancer and her surviving young children’s first question was whether their Mom was going to die since their baby sister had died of cancer. This was a tough question and one that my sister, and her husband, were not prepared to talk about, no less answer, given that they didn’t have any answers about her prognosis in the early stage of diagnosis and treatment. But her kids needed to know.

While my sister’s case may be an extreme, no healthcare professional can really know what history of death, dying, illness/disease, etc., a patient, and their family, brings with them when they arrive on the medical team’s doorstep with a cancer, or some other life-limiting or life-threatening diagnosis. What is known, however, is that children cope better with unknown or scary situations like an illness in the family, when they are talked to and told what is happening vs. being left in the dark. It’s natural for parents to want to protect their children and not tell them everything, but the fact is that being told the truth is often not nearly as bad as what the children will imagine in their minds as they try to “fill in the blanks” of what’s not being said or told to them about their parent’s illness and treatments.

My sister’s children had lots of other questions when told their Mom had cancer besides just “Was she going to die like their baby sister did?” They wanted to know if she would become bald, whether she’d have to stay in the hospital and importantly, would she ever come home from the hospital, or if she did, when would she feel better, would the medicines make her sick, would she get poked, would it hurt, and so many more. This was a family overwhelmed with a difficult cancer diagnosis and they were in need of help. At the time of diagnosis, the family requested help from the Doctor to tell the children of their Mom’s diagnosis with my sister and her husband present in the room, as well as with support from a Social Worker, to help diffuse any emotional blow-ups the kids might have. The Social Worker also helped to clearly, and at an age-appropriate level, objectively answer any and all questions they had. It wasn’t perfect, but it was a start in trying to keep the kids involved and informed about where this cancer journey would go for their Mom. It also opened the door for the kids to feel they could ask questions, as they arose, and that if Mom or Dad couldn’t answer them, they’d find someone who could.

While not every family may be this empowered or knowledgeable to ask for the kind of help within the healthcare system (or such help may not be available), my sister and her husband were and had no issues with asking for this supportive help when telling the kids about her diagnosis. However, when these resources may not be available, another alternative might be seen in a model currently in existence at the University of Michigan’s Comprehensive Cancer Center. At UofM, they have developed a program called, Families Facing Cancer, which is designed to help parents and grandparents prepare a plan of how, and what, they will share with the children/grandchildren on a level the kids can understand, and in alignment with the child’s/children’s temperament and learning style.
This program includes, as part of its offerings, a bi-monthly developmentally-appropriate “Come and Visit” Tour of the Cancer Center for the children aged 5-12 of adult patients, and their caregivers. The purpose of the Tour is to give the children of adult cancer patients (parents or grandparents) the opportunity to see and learn about the care their parent is receiving when they come to the Cancer Center for treatment. The walking Tour includes taking the children through the infusion center where their parent currently is, or maybe will be, receiving chemotherapy, during which time there are explanations given to the children about the medical environment and the equipment. They’re shown what IV chemotherapy looks like and told what kinds of effects it can have on their Mom or Dad, so they understand when they potentially see some of these side effects playing out at home. During the tour, they also meet members of the Cancer Center’s medical team who care for patients like their Mom or Dad; they also participate in a fun art therapy activity to help them process through any feelings, issues, or concerns they may have or that the Tour may have brought up for them. One such project is called “Hand-in-Hand” beads in which “beads are strung on a cord to represent the child’s unique qualities, significant moments, and positive interactions during a love one’s care. The child is encouraged to ask questions and express feelings during this activity, according to Sheila Morris, a former Child Life Specialist from the Patient and Family Support Services Department. Sheila goes on to say that the beads “honor the children and the bonds they share with their parent or grandparent.” To make it fun, the children also get to say “Hello” to the Therapaw dog and, of course, refreshments are also served.

As would be expected, the Tour is conducted in a way that makes the children feel “safe” during and after the Tour as it helps to demystify what happens when Mom or Dad come for treatments, why they may be sick from the treatments or lose their hair, etc. It also provides plenty of opportunities for the kids to ask any questions they have about the treatments, equipment, or anything else that may be an issue or concern for or about how the doctors will take care of their parent/grandparent.

The Tours are conducted on Saturday mornings when fewer patients are in the Infusion Center, but as such, there are precautions the Cancer Center needs to take to protect any patients who may be present for treatment during the Tour. Patients and visitors, children and adults, should not attend the Tour if certain symptoms are present or if they have been exposed to certain conditions that would put cancer patients at risk.

A Child Development Specialist is also available to meet one-on-one with the parents (in a separate visit from the Tour) to help create an individualized plan for talking with each of their children about the parent’s cancer care and treatments on a level that each will understand. Phone consultations are also available.

Resource kits are also available which include information on the following topics:

- How to talk with the children
- Help with parenting during the cancer illness and through recovery
- Books to read with or to children, per their developmental age, as well as books for Teens
- Community support programs

Printed resource materials and fun projects to help the parent stay connected with their child/children if they are hospitalized are also available through the Child Development Specialist with this program.

Tours and Q&A’s at the place where Mom or Dad get their cancer treatments go a long way towards helping to ease the questions, concerns, and worries that their children may have. It also helps to take some of the burden off of the parents with respect to how to approach talking about their diagnosis and treatments with their children. Importantly, when Moms and Dad with cancer avail themselves of counseling/training or resources to help them have these important conversations with their kids, it encourages more open communication and empowers parents to still parent and help their children through the parent’s illness. This hopefully will help so that each family member can remain whole as individuals, and together as a family unit, throughout the parent’s cancer care journey.
References:


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This is an "oldie but goodie." Published in 2004 in probably the most widely read and respected medical journal, this information pushed to the forefront the issue of disclosure of imminent death to the child.

**Abstract:**

**Background:** One of the questions faced by the parents of a child who is terminally ill with a malignant disease is whether or not they should talk about death with their child.

**Methods:** In 2001, we attempted to contact all parents in Sweden who had lost a child to cancer between 1992 and 1997. Among 561 eligible parents, 449 answered a questionnaire, and 429 stated whether or not they had talked about death with their child.

**Results:** None of the 147 parents who talked with their child about death regretted it. In contrast, 69 of 258 parents (27 percent) who did not talk with their child about death regretted not having done so. Parents who sensed that their child was aware of his or her imminent death were more likely to regret not having talked about it (47 percent, as compared with 13 percent of parents who did not sense this awareness in their child; relative risk, 3.7; 95 percent confidence interval, 2.3 to 6.0). The same variable was related to having talked about death (50 percent vs. 13 percent; relative risk, 3.8; 95 percent confidence interval, 2.6 to 5.6), as was being religious (42 percent vs. 25 percent; relative risk, 1.7; 95 percent confidence interval, 1.2 to 2.3). The child’s age was related to both having talked about death and the parents’ regretting not having talked about it.

**Conclusions:** Parents who sense that their child is aware of his or her imminent death more often later regret not having talked with their child than do parents who do not sense this awareness in their child; overall, no parent in this cohort later regretted having talked with his or her child about death.

**Who** is the audience for this information? Families of children with life-limiting illnesses and their health care providers should be aware of these data when they consider disclosure to the child concerning prognosis.

**What** is special about this article? Prior to this, the prevailing thought was that such discussions might stress the child and take away hope. While there were a few small studies that suggested that the child benefitted from open and honest communications, there was little information about the parents’ perceptions. That only 1/3 of the parents had talked to the child about death is surprising in today’s setting. That 1/3 of those who did not disclose imminent death regretted not doing so is not so surprising. And of those non-disclosing parents, half of those who sensed that the child was aware of imminent death regretted not talking about death. Of course, the child really doesn’t have a voice in this information. But
for parents, and health care providers who counsel parents, this article acted as somewhat of a “wake up call.”

Where and how can I apply this information? Certainly the information from this report can and should be shared with families who are uncertain about disclosure of imminent death to their dying child. Perhaps the child who is aware of the course of the disease who is not included in conversations about prognosis feels isolated and abandoned. The fact that there were no regrets about disclosure of imminent death supports a recommendation that communications with the child about expected course of the disease and prognosis be accurate and honest.
Conversations Matter NIH: National Institute of Nursing Research.


“In January 2014, the National Institute of Nursing Research (NINR), part of the National Institutes of Health, publically launched Palliative Care: Conversations Matter®, an evidence-based communications campaign to increase awareness of and improve communications around pediatric palliative care. The first phase of the campaign included materials designed to assist health care providers with starting and continuing conversations about pediatric palliative care with their patients and patients’ families. Three hospital systems completed an evaluation of the materials.

To develop the Palliative Care: Conversations Matter® campaign, NINR brought together parents and palliative care clinicians, scientists, and professionals to give their input and expertise on what they felt was needed in the field. In addition to extensive formative research, the Institute pilot tested the health care provider campaign materials for nine months in two health care systems to gather feedback from an interdisciplinary group of health care providers.

NINR is currently implementing a second phase of the campaign which focuses on patients, and their parents and families to raise awareness and empower families to begin a dialogue with health care providers. The Institute hopes that Palliative Care: Conversations Matter® will increase the use of palliative care for children and teens living with serious illnesses.”

Who is the audience for this information? All providers of care for children with life-limiting illnesses and conditions and their families will be interested in this information.

What is special about this information? Materials that are provided for health care providers, the child, and the family facilitate and support conversations about pediatric palliative care (PPC). Many of these are available in Spanish. The materials are free and can be downloaded from the website or ordered via phone or email. Family stories enrich the materials. By making PPC more understandable to families and conversations with providers more manageable, PPC should be more accessible and accessed by children in need of the services.

For example, there are materials for the child and family on

- Palliative Care for Children
- Pediatric Palliative Care at a Glance Fact Sheet
- Finding Family Support Resource Card
- A Family’s Perspective – Family Stories
- Pediatric Palliative Care: A personal Story
- Ask about Palliative Care

Materials for providers include

- Conversations Matter Customizable Tear-off Pad. This provides information to introduce and manage a conversation about PPC.
Where and how can I apply this information? This information can educate patients and families about PPC and help dispel some prevalent myths. Suggestions for sources of support should be well received by parents. One barrier for a provider to initiate such conversations is uncertainty about what to say. In the materials are suggested strategies to facilitate conversations between health care providers, and parents and children.

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Children with life-limiting or life-threatening conditions often have complex needs that require care 24 hours a day, seven days a week. The National Hospice and Palliative Care Organization (NHPCO) is committed to making the best-known practices in pediatric palliative and hospice care more widely available to care providers and increasing the availability of state-of-the-art services to families.

The National Hospice Foundation (NHF) is the fundraising affiliate for NHPCO, and works in partnership with NHPCO to improve care at the end of life throughout the United States. NHF provides the necessary funding for educational materials and trainings for clinicians, social workers, and other caregivers at the bedside of a child facing a serious or terminal illness. By supporting NHF’s pediatric initiatives, you can help ensure these children have the best quality of care available to them.

In addition to providing support and resources for pediatric care teams, NHF also offers pediatric patients and their families more moments together through the Lighthouse of Hope Fund. The Lighthouse of Hope Fund offers children and adults facing a life-limiting illness to have their dreams come true.

Ten-year-old Alex was diagnosed with hepatopulmonary syndrome and cirrhosis of the liver. When his clinical team at Caris Healthcare asked him what was important to him in life, Alex told them he loved to swim and go to waterparks. Through the support of our donors, we were able to send Alex and his family to a waterpark for a weekend, giving Alex an opportunity to just be a kid and forget about being a hospice patient for a while.

Hospice gave Alex and his family more memories together. With your support, we can help all children and families have more memories and better prepare for the future.

Donate now to support NHPCO’s work to improve quality and care and the end of life for children. Together we will provide better care by identifying, developing and disseminating practical strategies that advance care for children and families coping with life-threatening conditions, dying and bereavement.

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ITEMS OF INTEREST

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

1. **NHPCO Palliative Care Online Resources:**
   NHPCO has a variety of pediatric hospice and palliative care resources available at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics). Also, more palliative care resources are available at [www.nhpco.org/palliativecare](http://www.nhpco.org/palliativecare), including:
   - Community –Based Palliative Care
   - Legal and Regulatory Resources
   - Webinars and Courses
   - Plus more for NHPCO members

   **Palliative Care Programs and Professionals:** Join NHPCO Today!
   - [Individual Palliative Care Membership](http://example.com)
   - [Palliative Care Group Application](http://example.com) - Save by registering your entire team

2. **Pediatric Hospice and Palliative Care Resources:**
   - Courageous Parents Network – [www.courageousparentsnetwork.org](http://www.courageousparentsnetwork.org) 
     *Empowering parents caring for children with serious illness*

3. **Pediatric Hospice and Palliative Care Training:**
   - **NHPCO’s Fall Conference, The Intensives - Mastering What’s Next in Patient and Family Care,** October 31-November 2, 2016, Hollywood, FL.  
     Note: The conference will include a Pediatric Intensive titled, **Community Based Pediatric Palliative Care: Building Bridges for Future Success.** Register [HERE](http://example.com).
   - **2nd Annual Pediatric Palliative Care Coalition Conference,** October 27, 2016, Pittsburgh, PA. Sarah Friebert, MD, FAAP, FAAHPM (Director of the Haslinger Family Pediatric Care Center at Akron Children’s Hospital) is the featured keynote speaker who will discuss “National Trends in Pediatric Palliative Care.” Information is available at [www.ppcc-pa.org](http://www.ppcc-pa.org).
   - **NHPCO’s 32nd Management and Leadership Conference**  
     Preconference Dates: April 29 -30, 2017  
     Main Conference: May 1-3  
     Washington Hilton, Washington DC  
     Call for Proposals open, **deadline August 17, 2016** midnight, ET.  
     Exhibit Fact Sheet and Application.

4. **Journal / News Articles**
   - **NIH resources to help families navigate pediatric palliative care.** Read more [here](http://example.com).
   - **End-of-Life Care for Adolescents and Young Adults.** Little is known about end-of-life (EOL) care for adolescents and young adults (AYA) with cancer. How often do AYA Medicaid patients use hospice versus intensive measures? Read more [here](http://example.com).
5. **Subjects and Contributors for Future Issues of this E-Journal**
   For upcoming 2016 E-Journal issues, we plan to address issues related to: Pain Management and Symptom Management. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at christytork@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

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

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