ChiPPS Pediatric Palliative Care Newsletter

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Issue Topic: Education, Training, and Resources for Pediatric Palliative and Hospice Care

Welcome to the twenty-fifth issue of the ChiPPS electronic newsletter. This issue of our e-newsletter offers a PDF collection of articles that explore some issues involving education, training, and resources for work in the field of pediatric palliative and hospice care. We hope the articles in this issue will be especially useful for those who are new to working in this field and/or to those who have previously worked primarily in palliative and hospice services for adults. These are, of course, merely a limited number of the vast assortment of issues that arise in this broad subject area. Nevertheless, we hope this sampler will help to bring out some useful discussions and guidelines for readers of this issue.

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

Comments about the activities of ChiPPS, its Communications Work Group, or this issue of the newsletter are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues of this newsletter. Please contact Christy at torkc@sbcglobal.net or Maureen at Maureen.Horgan@providence.org.

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.
Issue #25: Education, Training, and Resources for Pediatric Palliative and Hospice Care
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Scott Newport
Scott, Evan’s father, captures in his profoundly poetic voice an essential element of caregiver healing—listening.

A Family Leading the Way with a Purposeful “Teachable Moment”  p. 5
Ann Fitzsimons, BS, MBA
Ann’s sister leaves a lasting legacy to one Resident MD by challenging him to embrace truth telling when communicating bad news. Communicating the truth that curative treatment is no longer an option requires courage and a belief that palliative care and hospice teams will continue care with aggressive comfort management.

Inter-professional Education and Telling Stories in Pediatric Palliative Care  p. 8
O.J. Sahler, MD
Dr. Sahler provides an outline for “inter-professional education”—any educational endeavor in which learning takes place between and among individuals from different disciplines and professions. This learning method invites dialogue and storytelling “that transcends time and space and is highly likely to carry a lesson” for effectively teaching about pediatric palliative care.

Education in Pediatric Palliative Care  p. 11
Jody Chrastek, RN, DNP, CHPN
A practitioner in the field for many years, Jody provides an inspiring perspective on expanding the model of pediatric palliative care education. She challenges providers to educate by providing a vision and passion that draws learners in and motivates them to action to assure children receive the best possible palliative care services.

Utilizing a Simulation Lab with Actors to Deliver Pediatric Bad News  p. 14
Kelly Komatz, MD, MPH, FAAP
The simulation lab at University of Florida College of Medicine Jacksonville offers a dynamic environment for the interdisciplinary team to practice communication of bad news to families with a seriously-ill child. Dr. Kelly Komatz provides an overview of the lab’s design and suggests that it is an effective way to practice communication skills and get immediate feedback. The model can easily be re-created in other educational settings.

Pediatric Palliative Care Collaborative Research: Coloring in the Picture in our Sphere  p. 16
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Pediatric palliative care physicians Sarah Frieber and Chris Feudtner provide an overview of the collaborative work of “Peppercorn” (PPCRN: the Pediatric Palliative Care Research Network). They also provide a summary of lessons learned and future directions for pediatric palliative research given the group’s recent Prospective Multicenter Cohort Study.

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Pediatric hospice chaplain, Ben Files, provides an overview of The Pediatric Chaplain Institute which he attended in September 2011.
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An extensive compilation of educational resources addressing pediatric palliative care and hospice themes.

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This booklist is provided as an inventory of published books with palliative care themes that may be considered for clinical use with children; it is not a formal recommendation.

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November is National Hospice and Palliative Care Month
NHPCO and all the members of the ChiPPS workgroup extend best wishes for a happy and healthy National Hospice and Palliative Care Month – an important time of outreach and recognition!
WHAT DRIVES US TO DELIVER CARE?

Scott Newport,  
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Are we expert fixers?  
With a scientific,  
Ten step method  
That always works

Or are we listeners’  
To those who are broken  
Joining them on a path  
To recovery

Occasionally our path to healing  
Is after a loss  
Grappling with hardship  
“Fortitudine Vincimus”  
(By endurance we conquer)

Healing is what drives us  
Listening is our method  
And we never give up  
Even if they have to  
Repeat themselves  
Ten times  
Or more

So what drives you?
A FAMILY LEADING THE WAY WITH A PURPOSEFUL “TEACHABLE MOMENT”

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Education in pediatric palliative and hospice care can come in many different forms and the majority of it generally is a “top-down” approach, starting at the medical and nursing schools and being pushed down to the med students and other professionals. This education can be delivered via lecture, video, “hands-on” practical training, grand rounds, and the like. And while it’s true that our patients are our “greatest teachers,” it can be an incredible (and hopefully long-lasting) learning experience when the family purposely decides to be a “teachable moment” so that the education can continue on a very real life, personal level. The following is an example of such an instance, and although not pediatric in nature, still has applicability to the healthcare teams serving our pediatric populations as this example is not an isolated incidence, as we well know.

My sister had been diagnosed with terminal Stage IV Colorectal Cancer in October, 2004. At that time, her Oncologist was hoping to buy her 2-3 years; the reality was she got about half of that. After a 14-month battle of an unsuccessful surgery to remove the tumor, then radiation and chemo to try and shrink the tumor (which was only partially successful), my sister continued on a palliative regime of chemotherapy to keep the tumor from impinging on her spine and to try to keep the other areas affected by the cancer at bay for as long as possible. She was comfortable and able to lead a relatively normal life for most of this time until January, 2006.

It was at this point that the tides turned and we knew something was changing. She resisted going into the hospital as I suspect she knew it was the beginning of the end. Finally, when she was so beaten down and worn out, she agreed to let me take her in. Unfortunately, the Clinical Oncologist who was managing her care was away at a conference, so we dealt with a plethora of other Drs. and medical personnel we did not know, nor did they know us. Every day, the same group of Hem-Onc Doctors, Attendings, Residents, etc., would round (all 8-10 of them). They would come into her room, report their latest theories on what was causing her pain and symptoms and inability to really eat anything, and then leave to schedule her for yet more tests to “get to the bottom of this.” We were never really given any real results or opinions of where we were really at with this, yet this same scenario would play out day after day.

Finally on Day 4, we, the family, decided to take the bull by the horns. When the posse of Hem-Onc Drs. rounded, we explained to them that “the elephant was in the room” and that this family wanted to talk about what we suspected was very bad news about her condition. We did not want them to put her through yet more invasive tests only to tell us that this was the end. We told them we did not need them to be 90% sure of the diagnosis so that then, after days of wasted time in the hospital, they could feel confident that there was nothing else they could do for her. 50% sure was good enough for us. We had a Plan B, which was for her to be released and discharged to a hospice care facility near her home so her husband, three young boys, and close family and friends could enjoy their final days with her. She did not want to die in the hospital and we made all of this very clear to this medical team…to the point of begging them to engage in “The Conversation” with us and let us know what they thought was going on…was this something that was “fixable,” or had the cancer finally gained the upper hand. This Medical Team assured us we were not “there” yet, and that they would let us know what the yet next new round of tests showed.

At this point, it also occurred to me that some of this “stalling” may have been intentional—were these Drs. trying to buy themselves time so that they didn’t have to be the ones to tell her she was dying? Were they really waiting for her Clinical Oncologist to return from his conference so that he could deliver the
“bad news”? Could no one in this healthcare system tell her this was the end? While just a fleeting thought, it had some merit in my mind.

As it turned out, this is exactly what happened. Her Clinical Oncologist returned to the hospital from his conference and came to her room to tell her she had some options (i.e., go home with some kind of IV treatment and see if it helped, along with some other in-home treatment), but it was apparent from his delivery that his heart didn’t really believe they’d make a difference. He had become attached to her and he was “throwing her a bone” because he also didn’t have the heart to tell a 44-year-old Mom of 3 that “there was nothing more they could do for her and that it was over.” He told her this was “bad, very bad,” but never told her she was dying. From my sister’s vantage point, she needed to be let off the hook. She needed her medical team to tell her that it was done… that we were at the end of the line and that there was no other curative or even palliative treatments they could offer her that would help her gain more time. She needed this because she couldn’t feel like she was the one who’d quit, to the disappointment of her family and friends. In the end, her Dr. never did tell her she was dying or that there was nothing more they could do for her. He forced her to make the decision to not continue with any of his treatments. He asked her to think about it overnight and told her he’d come back the next day to spend some time with her and get her decision.

He wasn’t out the door a minute when my sister looked at me and asked, “We’re done, aren’t we?” We both intuitively knew (and probably had known for days), yet we continued to wait for the medical team to tell us such, which they never really did. While a hard and painful decision, we knew there were no other options… that the cancer had “won” and that in the end we had had to make that decision without the help or guidance of our healthcare team.

The following day my sister decided to discharge from the hospital and go home under hospice care. Staying true to his word, her Clinical Oncologist did return to her bedside to get her decision and was not surprised by her choice. And then, in a gesture that I will never forget, he spent an hour and a half with her so that she could talk about her journey. She had a need to thank him for pulling her through this at points along the way when he made her believe in herself when she’d lost faith and hope. So while he hadn’t “done the right thing in the end by telling her she was dying,” in my sister’s eyes he redeemed himself in spades for the time he’d spent at bedside with her before she left. The three of us laughed and cried, the Dr. included, and said our good-byes. It was a fitting end to what had been a great partnership throughout her cancer journey.

Now while there are lessons to be learned from the story thus far, the real “teachable moment” came the next morning when my sister was being discharged. While we were waiting for all the hospital paperwork and the hospice papers/medical equipment orders/meds, etc., to be completed, we heard a knock at the door, and there, to our shock and surprise, was one of the Residents who had been in the Hem-Onc group of Drs. who’d rounded on her in the hospital while the Clinical Oncologist was at his conference. He asked if he could come in and we said yes. He approached us with a bit of trepidation and softly said, “We’re not good at this.” In order to really be a “teachable moment” for him, I quickly decided to really push him and put him on the spot and said, “at what part of this.” He then went on to explain that as Drs. they don’t know how to tell patients they’re dying. He admitted they all knew it from the early-on test results, yet all their training tells them to continue to try, to push, to find an answer, any answer, that might help the patient live, gain more time, be cured, whatever it might be. He admitted that he felt horrible as he watched us beg for them to engage us in the conversation about where we were “really” at with her condition and he wished he could have bucked the medical hierarchy (i.e., spoke out over the Attending and the Chief Hem-Onc Dr. rounding with them) and tell us, but the system didn’t work that way. I thanked him for his honesty and was glad that we had “gotten under his skin” and told him, in no uncertain terms, to never do this to another family again. That if his “Spidey senses” bingle and tell him something doesn’t feel “right” (as in him watching us beg to have the end-of-life conversation while his stomach is churning and his gut is wrenching), then it’s probably not “right” and he should do something.
about it. That maybe he can lead the “higher-ups” with his conscience and teach some old dogs with some new ways. He hugged us and thanked us for our understanding and as he left, I knew that this experience had left him forever changed. That he would not forget my sister or this family and the lessons we had taught him…lessons far more valuable than any lecture or grand rounds ever could.

While most families may not be as “self-aware” of the opportunity as we were (given my work in pediatric palliative/hospice care) to be a “teachable moment” like this, they do teach by their words and actions each and every day. Every encounter with them is, in a way, a “teachable moment.” A chance for us, as their healthcare team, to live and learn with them and from them and improve how we care for them...and for the many families we have yet to meet. The book learning and practical training is important, but perhaps they best learn “how to break bad news” by being honest and open with families…by telling the truth. And yes, while it's hard and painful for them, it's far worse for the families to suffer through lost days in a hospital when they could be at home enjoying precious time with their families. These exposures and interactions with our pediatric families can perhaps most benefit the “newly initiated” into the healthcare system (the Med Students, Residents, Attendings, etc.) so that they can learn new, better, more open ways of communication when families want and/or need to have those very difficult conversations about changes in the child’s condition, or that there really is nothing more that can be done...that it is the end of the child’s life.
“How can you take care of dying children?” is a question just about all of us who work in pediatric palliative care are asked time and again. The first time I was asked the question, I admit I was taken aback and clearly had to stop and think about what it was that makes the work—sometimes sad if not very sad—but always rewarding: it is the strength I get from the kids and their families. Then I tell a story, and the questioner nods and says, “I see what you mean.” Every once in a while, the questioner will add, “I want to do it, too.”

There is so much to know in pediatric palliative care: giving bad news, stages of grief, pain management, explaining death to children and their young siblings, helping parents through perhaps the most profound loss of their lives, helping to answer the question of what happens next, handling anxiety, anger, and guilt (our own as well as that of others).

The question then arises: how do we teach it all? I’ve long been a proponent of bringing our trainees with the team whenever we have a task to do so that they can be in the moment with us. They can observe, hear the question/the cry for help/the resignation/the anticipation/the fear, think about what they would say in response, hear our response, and watch the conversation unfold. And, later, debrief with us so that we all learn from the experience. It takes willingness to not be defensive or dogmatic on the teacher’s part and a willingness to be curious and analytical on the learner’s part.

Unfortunately, not every issue can be addressed in person. However, we have many other ways to instruct: we can give lectures, provide handouts, or assign reading lists. But these are abstract and rarely convey the personal qualities that are the real heart of what it means to provide palliative care, especially when the child and family have entered into the last stages of the child’s life.

One avenue that I think we may not use enough is hearing the story. I would go further to say hearing the story in the company of listeners from other professions that, together, form a complementary whole.

Interprofessional education is a pedagogical notion that has been with us for almost a generation. It is defined as any educational endeavor (workshop, seminar, small group exercise) in which interactive learning takes place between and among individuals from different disciplines or professions. The interactivity among the participants is the key ingredient because it is the vehicle for learning about how the other discipline views the world and how this worldview frames what role the discipline plays, and how the various disciplines might work together to form a functional team.

An essential caveat in considering interprofessional education is that it is not reserved for students except as we all are students. Thus, the educational wealth that can be derived from learning from others who approach life from a vastly different perspective is open to all of us.

I began this essay remembering that my answer to the question, “How can you take care of dying children?” was to tell a story. In a recent issue of the Journal of Interprofessional Care, Campion-Smith et
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al (1) report on their experience with narrative analysis as a change agent in palliative care. In this study, an interprofessional group met six times and used narratives as the basis for discussion of issues in palliative care. Participants shared stories from their professional experience in facilitated small groups. One session included a caregiver who read from her diary about the death of her husband. The course was attended by physicians, nurses, social workers, and emergency care practitioners. Discussions were designed to focus on feelings rather than medical management. At follow-up about five months later, telephone interviews with 19 of the 28 participants found that many described changes in professional behavior that they believed had led to improved patient outcomes.

What is it about story telling that makes it such a compelling learning tool? Perhaps part of its appeal rests with the willingness of the teller to open himself or herself up to scrutiny if the story entails sharing a personal experience. Another part of its appeal may be that it deals with a real situation that carries with it enough emotion (whether angst or relief) that it has remained with the teller months or even years after the event. To have made such an impression means that the story has personal value that transcends time and space and is highly likely to carry a lesson worth passing on.

What stories do I tell others that I hope will convey the richness of the gifts that patients and their families have given me and that will help them be less fearful of engaging in the work of pediatric palliative care?

There is the story of Donnie who, at age 14, was suffering from end-stage cystic fibrosis and was admitted to the hospital for the fifth time in as many months the day before I was to leave for vacation. “Dr. Sahler,” he said as I entered his room (which was the first time he had ever called me by name rather than, I thought, thinking of me as that lady who wanted him to talk about his feelings about having CF), “I don’t want to die.” It’s amazing how relieved I felt that he hadn’t asked me if he was going to die. “You’ve been thinking about it. Tell me what you’ve been thinking.” “They need to find a cure this weekend.” “I know they’re working very hard to find a cure, Donnie, but I don’t know if they’ll find it this weekend.” “I know, but it has to be this weekend.” “Has Dr. X (the pulmonologist) been straight with you?” “I want him to be the same this weekend as he always is.” “May I tell him that? I have to go by his office on my way to my own office.” “Yes, tell him to be the same this weekend as every other weekend.” We hugged, which we had never done before, and we said “goodbye” not “I’ll see you again.” Donnie asked members of his church to stay with him and he died on Sunday evening.

Or the story of Mary, a 7-year-old girl with end-stage renal disease from undiagnosed pyelonephritis who could not be weaned off the ventilator following a kidney biopsy. After a week, it was discovered that she also had a totally unrelated degenerative neurologic disease and it was highly likely that she would never breathe again on her own. She was in the second grade at a Catholic school. Her maternal grandmother had died a year before and Mary believed that her grandmother was in Heaven. After Mary had been on the ventilator for two weeks, her mother decided that if God wanted Mary to breathe on her own, He would let her do that. Taking Mary off the ventilator was set for 11 o’clock in the evening. Her mother felt that she could not be at the bedside and asked the nurses to call me in to be with her daughter while she sat alone in the hospital lobby. I held Mary’s hand as she was extubated. Her eyes became very wide and she held my hand tightly. I told her that, if it were time for her to go to Heaven, her grandmother would be waiting for her and the two of them could bake cookies, which I knew they liked to do together. Mary held tight. And then I told her that I didn’t know for sure, because no one had ever died and come back to tell about it, but I didn’t think it would hurt. She closed her eyes and let go of my hand.

One day, I sat with Tom, a 17-year-old boy who had metastatic cancer and had been hospitalized for most of the past two months. I said to him that I thought he looked tired. He told me that he was but he had to keep fighting because he didn’t want to disappoint his mother. I met with his parents an hour or so later, and made the observation that Tom looked tired. His parents agreed and said that they didn’t know what kept him going. I suggested that he might be fighting because he didn’t want to disappoint them. They quickly responded that he shouldn’t feel that way. They knew what a courageous battle he had been
fighting for years. I suggested they consider telling him that. The next day, it became clear that Tom probably had pneumocystis pneumonia. He was scheduled for a CT scan the next morning. I sat with the parents in the X-ray waiting room. They told me that Tom had decided that if the pneumocystis was in one lobe, he wanted to have surgery, but if it was disseminated, he didn’t want any more treatment. The radiologist appeared moments later and told the parents that the pneumocystis was disseminated. They looked at me and said, “We know what Tom wants us to do.” Tom was a great NASCAR fan. Despite the fact that I absolutely do not understand the point of the race, I never see an advertisement or hear about NASCAR that I don’t think of Tom.

Telling these stories now takes me back almost 35 years. I admit that I have told them and others many times by way of illustrating a point or suggesting a course of action for one of our trainees or practitioners who are struggling with their own Donnie or Mary or Tom. In some instances, I am fortunate to have a student or colleague in nursing, the clergy, or social work help me interpret these experiences in new ways that add even more to the richness of purpose and incredible strength that working with these patients and others have brought me over the years.

How much more fortunate could I be?

Reference

EDUCATION IN PEDIATRIC PALLIATIVE CARE

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Pediatric palliative care education offerings have grown rapidly in the last decade and continue to develop. Online courses, seminars, and conferences are available. Yet somehow there is still a shortage of palliative care services for children. We know that a major reason for this is a lack of trained professionals. So why is this? Many readers of this newsletter have been involved in providing education formally or informally on a regular basis. I would guess that at times you might have found your audience smaller or less responsive than you had hoped. This is often the case—but why and what can we do?

First let's take a step back and look at the educational process as a whole. Think about what you were most eager to learn. No doubt it was something you either really wanted or needed to know about. For example, as teenagers most of us were desperate to learn to drive. We did not have to be pushed or cajoled to attend classes. It was what we wanted, longed for, and saw the desperate need for it (even if our parents may have dreaded the day!)

It is that internal drive that pushes individuals to learn. When you tap into that same drive for pediatric palliative care the learning will be a natural fit. It must be provided to meet the needs of the learner—formally or informally. It may be at the bedside of a child, at home, in a classroom or online. The setting does not limit the learning if the learner wants to learn.

Therefore it is essential that there is a personal connection or understanding of the need for the knowledge in their practice. When asked about providing pediatric palliative care, many nurses say, "I am sure someone else is taking care of kids who need hospice or palliative care. I don't think I need to deal with it." Unfortunately there is a need for this care and the hospice/palliative care community has the foundational expertise that with a little extra tuning and support can provide that care.

Education is essential but so is helping others see the need for education. The needs of the audience should guide the education. Some people want the facts while others are moved by real life scenarios. So for the fact seekers use facts. For example:

Although childhood deaths make up only 2% of the country's total deaths, that still means that there are 55,000 childhood total deaths annually (Field & Behrman, 2003). Although the majority of these deaths occur in the hospital (Carter & Levetown, 2004), the number of dying children cared for at home is increasing. However, the number of agencies offering hospice care for children remains far smaller than those providing care for the adult population. In 2007 the National Hospice and Palliative Care Association reported that out of the 4,500 member hospices across the nation only 378 reported being prepared to provide palliative or hospice care for children (Friebert, 2009). The 2003 Institute of Medicine (IOM) report When Children Die: Improving Palliative and End-of-Life Care for Children and their Families holds some answers to this question. In chapter 9, the report details the lack of pediatric palliative care education and training for health care providers in both nursing and medicine. So this shows there is a need for this care but a lack of services. As health care providers we seek to meet the needs of patients and families with the tools we have. For some people knowing the facts will move them to action.

Other individuals may understand the needs better from hearing how this inadequacy affects individuals. For example, by relating a true story:
A family had just received the news that their baby, who had undergone multiple investigations and interventions in NICU, was now dying. The family was from a small town and longed to return to the love and support of their close-knit community in this tragic time. The hospital hospice team contacted their local hospice director who did not hesitate to extend their services. The family started their long journey home at 4 pm on Friday. When the on-call nurse came on and found the new admit was a baby, she panicked. “We don’t do peds do we???? I have no training, I don’t feel competent! I won’t do it.” The family was in the car on their way home and they were not turning back. The baby died that night with no hospice services. This sort of thing would not have happened to an adult but tragically did for this infant and family. We must improve this situation across the country. We must all work together to make sure children get at least the same end-of-life care as adults.

The use of facts or personal stories can be helpful, but ultimately the educator must help the learner see their need for education. The common question of WIFM (what is it in it for me?) is actually a great starting point for helping people be able to see that TIAIFM (there is a lot in it for me). It is the role of the educator to help people see how it applies to them which allows learning to happen more effortlessly. The presence of an eagerness and openness to learn will ensure more effective educational outcomes than any flashy or animated PowerPoint.

Many ChiPPS readers know a lot about pediatric palliative care. I encourage you to share it with your colleagues and others. Even if it is just to share an article you read or a challenge you have successfully addressed in peds palliative care. Listen to what they identify as their needs. Ask them what is the hardest thing about caring for children that are dying or living with life-limiting conditions. What are their worst fears? When people feel heard and see their own fears or concerns being addressed they listen and learn more easily.

Education can take place at the bedside, in the office, in the break room, or in a formal setting. But wherever it is the most important aspect of it is what the learner will do with it, will they use it to fill a need or lose it because they see no use for it.

There are many resources for education including online classes, books, web sites, and multiple webinars. Find out what the learner wants to know. If the learner is you, think about what you want to know and explore websites which can either meet that need or point to you a resource that meets that need.

There is always more to learn and the field of pediatric palliative care is growing by leaps and bounds. It is an exciting time to be part of this expanding field.

It has been said that palliative care education must include both the art and science of this discipline. However in order to produce exceptional palliative care professionals it must be more than that. It must be the sharing of a vision and passion that excites and draws in the learner to ignite the motivation to learn. Unless the learner has this motivation even the best teachers will be useless. In small and big ways we are all teachers and mentors. Consequently, it is essential that we realize this and find ways to help learners uncover their motivation. As the poet William Butler Yeats wrote “ Education is not filling up a pail, but lighting a fire.”

I encourage you to find the spark to light the fire in others and allow it to burn in yourself so that each of us may always be both learners and teachers.
References


Palliative care education for students of multiple disciplines related to healthcare is being recognized as an essential component for future nurses, physicians, social workers, and chaplains. With the advent of certifications in hospice and palliative medicine in most disciplines, how to provide education becomes a sticky wicket. There are often ethical and practical limitations, such as the vulnerability of patients and their families, when approaching developing competencies in the domains of palliative care. Perhaps the most challenging competency is skillful communication and personal interactions with patients and families. Simulation exercises with standardized patients provide a safe and supportive environment for the adult learner when faced with medical situations that occur with low frequency and high stakes, such as the need to deliver bad news in the pediatric setting.

This article will detail the development of a pediatric bad-news simulation exercise for post-graduate pediatric residents and fellows at the University of Florida College of Medicine (UF COM) - Jacksonville. Our experience is somewhat unique; however, it can be easily replicated at other institutions.

**History**

Third year pediatric residents at UF COM - Jacksonville have a mandatory rotation which includes pediatric palliative and hospice medicine. Feedback from the residents during the initial months of this rotation assisted in identifying gaps in their experiences related to approaching patients and families facing difficult decisions or “delivering bad news.” This prompted the development of a pediatric bad news simulation exercise for all pediatric residents and fellows in Jacksonville.

UF COM - Jacksonville has an established Center for Simulation Education and Safety (CSESaR) that is equipped to provide set-ups that resemble actual rooms in hospitals and/or physician offices, the capacity to audio and video tape the interactions during the simulation exercise, and a lecture room.

**Scenario Development**

Faculty members from the Department of Pediatrics were approached to assist in the development of the simulation cases and to facilitate the actual simulation. The faculty members included the residency director, a neonatologist, a pediatric infectious disease specialist, and a pediatric palliative care physician. The patient scenarios were developed after discussion between the faculty members and the chief pediatric residents. These scenarios included: a prenatal diagnosis of Trisomy 18, a new diagnosis of HIV in a teenager, recurrence of cancer after two bone marrow transplants in a teenager, and a compassionate terminal wean from the ventilator following severe head trauma. All of the case scenarios were drawn from actual patient cases encountered by the faculty members.

**Standardized Patients**

The patients and families were “actors” identified by the lead faculty members. These actors included the following: personnel from the local hospice agency (including nurses, social worker, and chaplain), nurse educators, and a local high school drama club. The actors from the hospice agency had previously
participated in adult-based scenarios and also have had personal experience in working with patients and their families in their assigned simulation and role-playing. The nurse educators likewise had previous experience in the simulation setting and also brought their own experiences to the exercise. The high school students were prepared independently to assume the role of a “teenager” and to react and interact with the physician delivering the new diagnosis.

**Simulation Day**

The American Medical Association Education for Physicians on End of Life Care “Delivering Bad News” lecture outlining the six step approach to delivering bad news was adapted to pediatric practice (ama-assn.org/ethic/epec/download/module_2.pdf). This lecture was delivered to the residents and fellows before the actual simulation exercise. This gave the participants a framework to guide their discussions and assisted in bringing a level playing field to the participants since they ranged from first year residents to second year fellows.

The four scenarios were run concurrently with the participants grouped so that each resident had to be the bearer of bad news at least once. The groups rotated through all four scenarios; thereby, each group experiencing all four scenarios. No two scenarios ever “played out the same” because the actors who served as simulated patients were able to respond in different ways to the particular resident/fellow throughout each scenario and to improvise as their interactions developed. Faculty members were present at each of the four scenarios and helped guide the scenario to a conclusion since each scenario was allotted 25 minutes.

**Feedback**

The residents reported two overall strengths of the exercise: actors assuming the roles in such a realistic manner and receiving immediate feedback from their peers, actors, and the faculty; thereby enhancing the learning activity. Discussions revolved around the participants’ own feelings regarding the exercise, as well as their comfort and discomfort in their interaction with the patient and/or family. The actors gave feedback as well to the participants to further enhance and develop their skills in interpersonal relations and communication. The faculty member was also able to use the scenario to further educate the participants to the “larger” picture related to each scenario. For example, the differences between palliative and hospice levels of care; the issues surrounding compassionate extubation; and adolescent confidentiality.

**Summary**

Can someone ever become the “expert” in disclosure of bad news? Is the discussion of bad news limited to those physicians who chose fields such as emergency and intensive medicine? OR are communication skills necessary for all physicians? The use of simulation exercises with standardized patients allows all healthcare professionals to hone their interpersonal and communication skills. Furthermore, support and feedback from peers, faculty, and the actors aids in the refinement of skills during the exercise with carry over into future patient and family interactions.
Thankfully, pediatric palliative care programs are growing throughout the country – not just as children die, but as they live longer with serious illnesses. As our numbers grow, so too does our obligation to demonstrate outcomes related to the services we are providing, both in terms of access and quality. Evidence-based inquiries into pediatric palliative care practice which are published in the medical literature will go a long way toward improving care for children and families, increasing the profile and acceptance of our field, and generating funding for service growth and sustainability.

To facilitate collaborative research in the field, a North American group of pediatric palliative care clinicians and researchers called “Peppercorn” (PPCRN: the Pediatric Palliative Care Research Network) has been collaborating for over 3 years. The network includes interdisciplinary representation from most of the major pediatric palliative care programs in the US and Canada. Earlier this year, the first group-wide study performed by this network was published in Pediatrics.1

“Pediatric Palliative Care Patients: A Prospective Multicenter Cohort Study” enrolled 515 children in palliative care programs at 6 children’s hospitals in the US and Canada (Children’s Hospital of Philadelphia, Children’s Hospital Boston/Dana Farber Cancer Institute, Seattle Children’s Hospital, Akron Children’s Hospital, Children’s Hospitals and Clinics of Minnesota, Canuck Place, and British Columbia Children’s Hospital). Patients were enrolled consecutively over a 3-month period (January 1-March 31, 2008) and then followed prospectively for 1 year.

In terms of demographics, the study cohort demonstrated the changing picture of childhood in palliative care. Although approximately half of childhood deaths occur in children under 1 year of age, the children in this study were evenly spread across the age continuum, with 17% under 1 year of age, 37.5% between 1 and 9 years of age, 30% between 10 and 18 years of age, and 15.5% age 19 years or older. There was a slight male preponderance (54%), and most patients were Caucasian (69.5%) and lived with both parents (60%). As expected, 73.5% had public insurance (i.e. Medicaid) or public and private insurance; 2.5% were uninsured. Most (72.6%) had siblings.

According to the study, the leading conditions among children in palliative care programs are genetic and congenital, affecting 40.8% of the children surveyed, followed by 39.2% with neuromuscular disorders, 19.8% with cancer (35% leukemia, 28% brain tumors, 35% solid tumors), 12.8% respiratory conditions, 10% gastrointestinal, 8.3% cardiovascular, 7.2% metabolic, 2.7% renal, 2.6% immunologic, and 10% other. Many patients (55%) had more than 1 major diagnosis.
Validating the picture of increasing medical and technological complexity that we see anecdotally in our patients, most of the children in the study (almost 80%) used some form of medical technology, including feeding tubes in 60%, central venous catheters in 22.3%, tracheostomy in 10%, non-invasive ventilation in 9.5%, and ventilators in 8.5%. Polypharmacy is also a common issue for this population: most were taking an average of 9.1 medications each, with a range between 0 and 18. The most common medications were acetaminophen, albuterol, lansoprazole, lorazepam, oral antibiotics, and morphine (used in 15% of the cohort). Symptoms experienced by the cohort to some degree validated previous studies, but also demonstrated unique aspects. In many published studies, usually involving children with cancer, fatigue is the most common symptom seen. For this cohort, in contrast, the most common sign/symptom seen was cognitive impairment in 46.8%, followed by speech difficulties in 46%, problems with enteral intake in 26%, seizures in 24.5%, and then fatigue in 23.3%.

The study group also described the characteristics of the consultative services provided by the involved palliative care teams. Established patients made up 64.3% of the cohort, and the remainder were new. Reasons for consultation included symptom management (58%), facilitating communication (48.5%), facilitating decision making (42.1%), assisting with logistics or care coordination (35.3%), assisting with transition to home (14.4), and advance care planning/DNR discussions in 12% (the numbers total greater than 100% because patients could have more than one). Reasons for consultation differed significantly between new and established patients: new patients were more likely to have as goals of the consult the provision of information, discussions about DNR status, peri-death recommendations, and transition to home; in contrast, established patients were more likely to have symptom management, decision-making assistance, and help with logistics or coordination of care as goals of the consult. Further, validating our interdisciplinary nature, the patients in this cohort received team recommendations for multiple other interventions for patient and family benefit, including social work, rehabilitation therapy, spiritual support, and volunteers or companionship.

What are the key lessons and future directions from the study?

- Only 30% of the cohort died over the 12-month follow-up period, and only 11.7% of the study population died within 30 days of palliative care consultation (early mortality). This means that **70 percent of children were alive one year after their first consultation**, cementing the reality that pediatric palliative care involves long-term, upstream integration into acute care that spans months, years and even decades. This figure surprises many outside the field, and reflects what we all know: we are involving palliative care earlier in a child's illness journey, a child's prognosis is more uncertain than an adult's, and children can be surprisingly strong.

- Most patients died in the hospital - 62.1%; 56% in an ICU; those who died at home were more likely to have cancer. An important but unmeasured demographic would be to ascertain what percentage of the patients died in their or the family's chosen location. If home is the desired location, further work needs to be done to make that option more available for children with non-cancer diagnoses.

- An unusually small percentage (17.1%) of the cohort was under 1 year of age, despite the fact that more than half of all pediatric deaths occur in this age group. This perhaps speaks to work yet to be done to increase the penetration of palliative care teams into NICU and fetal diagnostic settings.

- It is important for clinicians on pediatric palliative care teams to be able to handle many types of patients with different diagnoses, prognoses, and levels of care. Given the picture of the involved technology and medications, it is clear that most patients have complex and/or chronic conditions, so pediatric palliative care practitioners need to be well-trained in general pediatric as well as multiple subspecialty issues.

- Apart from unique medical trajectories faced by patients, most issues addressed in programs are universal, such as bereavement and psycho-social support for family members.
• Children in palliative care are often readmitted, which means we have to have a staff ready to handle new and established cases over the long term.

• Pediatric palliative care is a key part of high-quality care, particularly in terms of safety. Medication streamlining, comprehensive and holistic assessment, and coordination of care across handoffs and sites are just a few of the ways that palliative care improves safety and reduces medical errors.

Future plans for PPCRN include other descriptive as well as intervention-based studies. One possibility is that the New England Journal of Medicine study published in August 2010 showing palliative care improved survival outcomes in non-small-cell lung cancer patients could be “highly replicable” for certain pediatric cancers. Meanwhile, this study provides a broad-based look at children's hospital-based palliative care teams and puts forth a clearer picture of the work we are all doing.


The Pediatric Chaplains Institute (PCI) is an intensive, weeklong training that takes place each year to further the skills of chaplains who work in pediatric settings. The curriculum was developed by members of the Pediatric Chaplains Network and is taught by a group of chaplain faculty members. The class size is small—limited to twelve participants—so that learning can be personalized and relationships developed. The curriculum includes lecture, discussion, and activities on topics such as age-specific competencies, spiritual assessment, end of life, self care/staff care, medical ethics, and child abuse. In addition, time in the PULSE Center, a state-of-the-art healthcare simulations lab, provides an opportunity to put learning into action. The PULSE center brings in “standardized patients,” actors who are specially trained to re-create realistic healthcare scenarios. After each scenario, there is a debriefing that includes the ability to watch a video of the simulation and receive coaching from faculty and colleagues. Past participants have reported that the PULSE Center is the highlight of the week.

As someone who is relatively new to the field of pediatric hospice and palliative care, I found the PCI to be an invaluable learning experience for a number of reasons. For one, it provided a chance to connect with colleagues. Participants included people who are new to the field of pediatric chaplaincy, as well as those who have been practicing for many years, and the group was open to sharing knowledge and support. Next, the PCI helped me to improve my theoretical framework for doing chaplaincy with children of different ages, from neonates through adolescents. Most striking for me, however, was that the PCI infused new meaning into my work.
When thinking about the work of chaplaincy, especially in the beginning, I found myself getting caught up in what a chaplain does: listening, playing, providing emotional support, praying, rituals, charting, and the like. Those actions are important, but they are not the whole story. What I was reminded of at the PCI is what we represent in our work. In addition to representing our various professions, each of us on the transdisciplinary team represents compassion, kindness, and love as we go about our work. Even the smallest gesture is a chance to show our patients and families that we care about them and that they are not alone. This was a powerful and humbling reminder.

In this way, the PCI gave me both increased knowledge and renewed inspiration for my work. I am grateful to the faculty of the Pediatric Chaplains Network, the Arkansas Children's Hospital which hosts the training, the staff of the PULSE Center, this year's group of participants, and the Wilbert Foundation for their support. If you are interested in attending next year, please see this website: http://www.pediatricchaplains.org/Pediatric-Chaplains-Institute.aspx.
RESOURCES AVAILABLE FOR EDUCATION/TRAINING
IN PEDIATRIC PALLIATIVE/HOSPICE CARE

Compiled by

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Included in this compilation are some of the more well-known training sources and educational resources in pediatric palliative/hospice care. While this is not a complete list, it does provide some semblance of what’s available and additional information should anyone wish to explore these further.

<table>
<thead>
<tr>
<th>Program: Center to Advance Palliative Care (CAPC)-Pediatric Resources</th>
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<tbody>
<tr>
<td>Brief Description of PPC Education/Training</td>
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- The Center to Advance Palliative Care (CAPC) is a resource for palliative care program development and growth. It provides access to essential palliative care tools, education, technical training, and resources necessary to start and sustain successful palliative care programs in hospitals and other healthcare settings.
- The website lists publications, books and videos, policy statements, and other resources as a starting point for those exploring opportunities to provide pediatric palliative care services.
- It also houses on its website the Palliative Care Leadership Centers (PCLC), of which there are 2 Pediatric Centers. PCLC’s pediatric training and mentoring is tailored to pediatric palliative care programs at every age of development. The training and mentoring addresses all operational aspects of planning, starting, and growing a program.
- The 9-Section PCLC pediatric curriculum generally addresses the issues unique to pediatric palliative care program development and growth, including: Systems Assessment & Mission Alignment, Clinical Models & Staffing, Financial Case & Sustainability, Continuity of Care, Measurement, Internal Marketing, Palliative Care Education, Team Dynamics, and Program Implementation. However, the curriculum is tailored to each team’s needs.
- The PCLC Pediatric training locations include: Akron Children’s Hospital (Akron, OH) and Children’s Hospitals and Clinics of Minnesota (Minneapolis, MN).

| Audience |

- Appropriate for teams from children’s hospitals or pediatric programs within a hospital as well as hospices looking to start or sustain a pediatric palliative care service/program.
### Unique Points of this Education/Training
- Training consists of a 2.5-day, small group, hands-on format that provides the team with dedicated time together, away from day-to-day distractions and is provided by physician and nurse leaders in the field who are experts in applying effective pediatric palliative care models.
- Year-long mentoring is also provided to the team by the same physician/nurse leaders who participate in the training.

### Estimated Costs
- $7500 enrollment fee per team, which covers 2-6 people
- $7250 per team for those teams that include a hospital finance person
- $500 per person for each additional team member after 6
- Travel to PCLC hospital/hotel/other out-of-pocket costs extra

### Contact Information
- Website: [www.capc.org/palliative-care-leadership-initiative/training-and-mentoring](http://www.capc.org/palliative-care-leadership-initiative/training-and-mentoring)
- Contact: Jennifer Raiten
- Contact email: Jennifer.Raiten@mssm.edu
- Phone: 212.201.2683

### Program: Children’s Project on Palliative/Hospice Services (ChiPPS), a program of the National Hospice and Palliative Care Organization (NHPCO)

### Brief Description of PPC Education/Training
- The Children’s Project on Palliative/Hospice Services (ChiPPS) 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.
- ChiPPS’ mission is to build capacity by identifying, developing, and disseminating practical strategies that advance care for children and families coping with life-threatening conditions, dying, and bereavement.
- ChiPPS provides a variety of resources via its website, including: education via its pediatric palliative care quarterly e-newsletter and online training courses; online networking; outreach; pediatric palliative care policy updates/tools; standards of practice; facts and figures on pediatric palliative care and hospice; and materials for purchase for use in training of healthcare professionals and/or with/for families directly.
- NHPCO/ChiPPS sponsors a ‘Pediatric Intensive’ at NHPCO’s annual Clinical Team Conference. Next Clinical Team Conference and Pediatric Intensive will be November 5-7, 2012, Walt Disney World Dolphin Hotel, Lake Buena Vista, Florida. Call for proposals will be announced soon.
- ChiPPS’ online educational pediatric palliative care course consists of 10 modules: Principles and Standards; Delivery Models; Ethics,
### ChiPPS

**Children’s Project on Palliative/Hospice Services**

<table>
<thead>
<tr>
<th>Decision-Making, and Advance Care Planning; Childhood Development in Health and Illness; The Spectrum of Complex, Chronic, and Fatal Conditions; Assessment and Management of Pain; Symptom Management; Psychosocial Support of the Family and Community; Bereavement Care; and Structure and Support of the Interdisciplinary Team</th>
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<tbody>
<tr>
<td>Its other printed training materials are designed to help develop and implement individualized educational and training programs including: Pediatric Palliative Care Standards, among others</td>
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<tr>
<td>ChiPPS members collaborated with NHPCO and the DC Pediatric Palliative Care Collaborative to compile a Concurrent Care for Children Requirement: Implementation Toolkit (Section 2302) which details information on options available to states implementing Section 2302 or who are considering expansion of pediatric palliative services to children in their communities</td>
</tr>
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</table>

### Audience

- Healthcare professionals involved in caring for pediatric patients under palliative and/or hospice care

### Unique Points of this Education/Training

- Education and training is on demand web- or manual-based, so it can be done as healthcare professionals and/or organizations have time to conduct or schedule it
- Training is just not focused on practitioner-training, but also on policies and quality standards, broadening the scope of the education beyond traditional methods and content
- Educational materials are developed by some of the foremost leaders in the pediatric palliative care/hospice community in their respective fields

### Estimated Costs

- Tuition for NHPCO’s Pediatric Palliative Care Online training courses: $70 (member), $140 (non member)
- NHPCO/ChiPPS resources: available to download for free at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics)
- Books: Varies—See the Marketplace Section on the NHPCO website ([www.nhpco.org/marketplace](http://www.nhpco.org/marketplace))

### Contact Information

- Website: [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics)
- Contact: Gwynn Sullivan, Pediatric Liaison, NHPCO
- Contact email: gsullivan@nhpco.org
- Phone: 703.647.5169

### Program: End-of-Life Nursing Education Consortium (ELNEC)

### Brief Description of PPC Education/Training

- ELNEC is a national education initiative to improve palliative care, administered by the American Association of Colleges of Nursing (AACN) and the City of Hope
- The core content is divided into 8 modules: Nursing Care at the End of Life; Pain Management; Symptom Management; Ethical/Legal

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).
<table>
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<tr>
<th>Issues; Cultural Considerations in End-of-Life Care; Communication; Loss, Grief and Bereavement; and Preparation for and Care at the Time of Death</th>
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<tbody>
<tr>
<td>• Participants receive a comprehensive 1,000+ page syllabus, palliative care textbook, and a wealth of resources and strategies to teach this content to others</td>
</tr>
<tr>
<td>• ELNEC-Pediatric Palliative Care was developed by 20 pediatric palliative care experts in 2003, being adapted from the ELNEC-core curriculum</td>
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<tr>
<td>• In 2009, the pediatric palliative care curriculum was updated to include enhanced perinatal and neonatal content</td>
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<th>Audience</th>
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<tr>
<td>Unique Points of this Education/Training</td>
</tr>
<tr>
<td>• Undergraduate and graduate nursing faculty; CE providers; staff development educators; specialty nurses in pediatrics, oncology, critical care and geriatrics; and others nurses (so they can teach the essentials to nursing students and practicing nurses)</td>
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<tr>
<th>Estimated Costs</th>
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<tr>
<td>• Over 12,750 nurses and other healthcare professionals have been trained through the program in total; with more than 1600 of these in the pediatric program</td>
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<tr>
<td>• Curriculum is revised regularly based on participant recommendations and new advances in the field, and is modified for each distinct audience</td>
</tr>
<tr>
<td>• ELNEC trainers can consult/partner with other trainers and those outside the ELNEC network can use the website to contact experts as consultants and instructors for their own programs.</td>
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<tr>
<th>Contact Information</th>
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<tr>
<td>• $550 registration fee (Note: If 3 or more professionals attend from the same institution, they receive $50 off their registration)</td>
</tr>
<tr>
<td>• The registration fee covers: 1000+ page syllabus (includes objectives, overview, participant outline, ppt. Slides with talking points beneath each slide, case studies, and supplemental teaching materials); CD-ROM that includes all the information found in the syllabus; 2010 edition of the Oxford Textbook of Palliative Nursing, 4 meals (2 continental breakfasts and 2 lunches and snacks); CE’s; and the opportunity to network with pediatric nurses from across the US</td>
</tr>
<tr>
<td>• The ELNEC Pediatric Curriculum Modules are also available as online training through Hospice Education Network (<a href="http://www.hospiceonline.com">www.hospiceonline.com</a>)</td>
</tr>
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</table>

| Website: [www.aacn.nche.edu/elnec](http://www.aacn.nche.edu/elnec) |
| Contact: Pam Malloy |
| Contact email: pmalloy@aacn.nche.edu |
| Phone: 202.463.6930, Ext. 238 |
| For a list of ELNEC trainers by state for the various ELNEC courses offered, go to: [http://www.aacn.niche.edu/ELNEC/trainer.htm](http://www.aacn.niche.edu/ELNEC/trainer.htm) |
Other Pediatric Palliative/Hospice Care Educational Resources for Healthcare Professionals

Textbooks


Internet/Web-Based

ACT & Children’s Hospices UK:
- Produces a range of publications and resources for healthcare professionals to deliver the best possible care to children, young people, and their families. They provide professionals with a range of tools, guidance, information, and publications to support their work. Website includes the following sections for professionals: Care pathways for babies, children, and young people; Transition; End-of-Life; Networks; Education and Practice; and Workforce development. Many of these pathways and resources can be downloaded for free from their website
- Just recently launched their 30 Million Stars website which showcases all the projects and resources that were funded by the Department of Health for children’s palliative care in England (www.30millionstars.org.uk)
- www.act.org.uk

American Academy of Pediatrics (AAP)
- Organization is committed to attainment of optimal, physical, mental, and social health and well-being for all infants, children, adolescents, and young adults
- Has within it a Section on Hospice and Palliative Medicine (SOHPM), chaired by Dr. Sarah Friebert, MD, FAAP, FAAAAHP
The Section includes a Home page defining palliative care for this audience, In the News updates on pediatric palliative care, and Professional Education & Resources

www.aap.org/sections/palliative

American Academy of Hospice and Palliative Medicine (AAHPM)
- An organization of physicians and other healthcare professionals dedicated to excellence in hospice and palliative medicine and the prevention and relief of suffering among patients and families via education, clinical practice standards, research, public policy advocacy, etc.
- Publisher of the Journal of Pain and Symptom Management
- www.aahpm.org

Association of Pediatric Oncology Social Workers (APOSW)
- A group of professional oncology social workers whose efforts are focused on enhancing the lives of children with cancer and blood disorders and the families who care for them
- This is done through clinical social work practice, research, advocacy, education, and program development
- www.aposw.org

Canadian Virtual Hospice
- Website that provides information and support on palliative and end-of-life care, loss, and grief.
- Featured content for professionals includes: Tools for Practice and Courses and Conferences
- www.virtualhospice.ca

Center to Advance Palliative Care (CAPC)
- A resource for palliative care program development and growth which provides essential palliative care tools, education, technical training and resources for starting a successful palliative care program
- Houses the Palliative Care Leadership Centers, of which two provide pediatric training and mentoring tailored to pediatric palliative care programs at all stages of their development
- See Detailed Summary of this resource elsewhere in this Compendium
- www.capc.org

Centre for Pediatric Pain Research
- An interdisciplinary leader in children’s pain research that is dedicated to conducting high-quality research on how to better understand, assess, and manage children’s pain and translating this research into improved practice
- The website includes an overview of their work as well as useful resources on pain assessment and management in children. It also has a Pediatric-Pain Mailing list, which is an international forum for informal discussion of any topic related to pain in children (LISTSERV@lists.dal.ca)
- www.pediatric-pain.ca

Children’s Hospice International (CHI)
- Founded to create awareness of the needs of children with life-threatening conditions and their families and how hospice care can meet those needs
- Created the PACC model (Program for All-Inclusive Care for Children and their Families) at six sites around the country; model is geared to reduce obstacles for these children while creating a continuum of care for children under hospice
- www.chionline.org

End-of-Life/Palliative Education Resource Center (EPERC)
• Is a repository for educational materials and information about end-of-life issues for healthcare professionals. Its featured resources include: Fast Facts, Educational Materials, News, Training, Articles, Links and a Pallimed Blog.
• www.eperc.mcw.edu

End-of-Life Nursing Education Consortium (ELNEC)
• A national education initiative to improve palliative care as administered by the American Association of Colleges of Nursing and the City of Hope
• Has developed a pediatric palliative care-specific training course that's available as a train-the-trainer seminar or via online education modules
• See Detailed Summary of this resource elsewhere in this Compendium
• www.aacmanche.edu/elnec

Hospice Foundation of America
• Provides leadership in the development and application of hospice and its philosophy of care with the goal of enhancing the U.S. health care system and the role of hospice within it
• Professional resources include those in Children and Adolescents, among other topics
• www.hospicefoundation.org

Hospice and Palliative Nurses Association (HPNA)
• A collaborative professional hospice and palliative specialty nursing organization with evidence-based educational tools to assist members of the nursing team with managing complex symptoms, educating healthcare providers and family about hospice or palliative care philosophy, ensuring quality nursing care delivery, among others
• Offers certification info, e-learning, publications for the team, position statements, quick info sheets, teleconferences, etc.
• www.hpna.org

International Children's Palliative Care Network (ICPCN)
• International network of organizations and individuals working in children’s palliative care services around the globe
• Publishes a newsletter on international pediatric palliative care advances and is looking to share/partner with pediatric palliative care programs in more developed countries to help those with less resources than their African and other third world members have
• www.icpcn.org.uk

The Initiative for Pediatric Palliative Care (IPPC)
• The IPPC curriculum is a tool to assist pediatric healthcare professionals to provide high quality care to children and their families. Its interdisciplinary and interactive educational resources include small group learning activities, videos, and facilitator's guides
• Curriculum materials can be downloaded for free from the website. Educational training videos must be purchased.
• www.ippcweb.org

National Hospice and Palliative Care Organization (NHPCO)/Children’s Project on Pediatric Palliative Services (ChiPPS)
• ChiPPS’ mission it is to build capacity by advancing care for children and families coping with life-threatening conditions, dying and bereavement. Is focused on sharing best-known pediatric palliative care practices and state-of-the art services to its members and the broader ppc community.
Children's Project on Palliative/Hospice Services

- Web-based pediatric palliative/hospice care resources include: Educational newsletter, online training, outreach to families resources, policy, quality/standards of practice, among others
- Specific pediatric educational resources include:
  - NHPCO’s Facts and Figures on Pediatric Palliative Care and Hospice
  - ChiPPS Quarterly peer-reviewed e-newsletter
  - Standards of Practice for Pediatric Palliative Care and Hospice
  - Concurrent Care for Children Requirement: Implementation Toolkit
  - Pediatric Palliative Care Online Training Series available through NHPCO’s E-Online.
  - Caring Connections – NHPCO’s consumer engagement program offering resources on planning ahead, caregiving, living with an illness, and grieving a loss. Brochures available for use with families from the website
- www.nhpco.org/pediatrics

Perinatal Hospice
- Is a clearinghouse for information on perinatal hospice and palliative care
- Includes resources for caregivers and parents, with downloadable birth plan templates and position papers available. Also includes a listing of known perinatal hospice programs across the country.
- www.perinatalhospice.org

Pregnancy Loss and Infant Death Alliance (PLIDA)
- Organization that supports healthcare professionals and patient/family advocates in their efforts to improve care for families who experience the death of a baby during pregnancy, birth, or infancy
- Resources include position statements, practice guidelines, conferences, a compilation of resources online, practice guidelines, etc., all related to improving care for the families they serve
- www.plida.org

Share/Pregnancy & Infant Loss Support, Inc.
- Their mission is to serve those whose lives are touched by the tragic death of a baby through early pregnancy loss, stillbirth, or in the first few months of life
- Offers professional resources on the website include articles, training and conferences, etc.
- www.nationalshare.org
PALLIATIVE CARE BOOKLIST FOR CHILDREN

Kris Catrine, MD, FAAP
Pediatric Hospitalist
Pediatric Palliative Care
American Family Children's Hospital
University of Wisconsin School of Medicine & Public Health
Madison, Wisconsin
kcatrine@pediatrics.wisc.edu

In conjunction with the Madison Public Library; updated 2010.

This booklist is provided as an inventory of published books with palliative care themes that may be considered for clinical use; it is not a formal recommendation.

**Picture Books**

*Abuelita’s Paradise* by Carmen Santiago Nodar
Although her grandmother has died, Marita sits in Abuelita’s rocking chair and remembers the stories Abuelita told of life in Puerto Rico.

*Alfie and the Birthday Surprise* by Shirley Hughes
The death of Bob’s cat prompts his friends and family to give him a surprise birthday party and a very special present.

*And What Comes after a Thousand?* by Anette Bley
Lisa and elderly Otto spend their days rambling around his farm. Otto always seems to have an "emergency" cookie in his pocket, knows how to make a slingshot and loves to count the stars. When Otto dies, Olga tries to comfort Lisa by telling her "Otto is like numbers. He's inside of us, and that will never end."

*Annie and the Old One* by Miska Miles
A Navajo girl unravels a day’s weaving on a rug whose completion, she believes, will mean the death of her grandmother.

*Badger’s Parting Gifts* by Susan Varley
Badger’s friends are overwhelmed when he dies, but as time goes on they begin to treasure their warm and loving memories of when he was living with them.

*Charlotte’s Web* by E.B. White
Classic story about the friendship of Wilbur the pig and Charlotte the spider. Charlotte teaches Wilbur much, including that all life must end.

*Children Also Grieve: Talking about Death and Healing* by Linda Goldman
A collection of shorter stories about the experience of loss for children

*Daddy and Me: A Photo Story of Arthur Ashe and His Daughter Camera* by Jeannie Moutoussamy-Ashe
Text and photographs provide insight into the relationship of tennis great Arthur Ashe and his six-year-old daughter Camera, showing how young children and their families deal with AIDS.
Eleanor, Arthur and Claire by Diana Engel
Claire, a young mouse, loves spending her summers with her grandparents, and although she finds things changed after her grandfather's death, she and her grandmother find the strength to go on without him.

Fireflies, Peach Pies & Lullabies by Virginia Kroll
When Francie's Great-Granny Annabel dies of Alzheimer's disease, Francie finds a way to help people remember the real person rather than the shell she had become as the disease ran its course.

The Foundling by Carol Carrick
Memories of his dog, killed in an accident, cause Christopher to resist his parents’ efforts to adopt a puppy. Parents try to rush their son through grief but come to realize then the child’s feelings are deep and long lasting.

Ghost Wings by Barbara Joosse
While celebrating the Days of the Dead, a young Mexican girl remembers her wonderful grandmother who sang songs, made tortillas, chased monsters away, and loved butterflies.

Goodbye Max by Holly Keller
Ben blames his parents for the death of his dog, Max, and does not want the new puppy they brought home.

Granpa by John Burmingham
A little girl and her grandfather share very special moments.

Helen the Fish by Virginia L Kroll
When six-year-old Hannah's beloved goldfish dies after a relatively long life, she seeks comfort from her older brother, Seth.

I'll Always Love You by Hans Wilhelm
Elfie, a dachshund, and her special boy progress happily through life together. One morning Elfie does not wake up. The family grieves and buries her.

I Miss You: A First Look At Death by Pat Thomas and Leslie Harker
Focuses on normalizing feelings of grief after the loss of someone close.

I Remember by Jennifer Moore-Mallinos and Marta Fabrega
A child loses a dog, available in Spanish also.

Jasper's Day by Marjorie Blain Parker
Jasper, an old dog with cancer, and his family celebrate his last day doing all of Jasper's favorite things. The book is sensitive to the family's decision to euthanize Jasper at the end of his special day and shows a family that loves and supports each other.

Jim's Dog Muffins by Miriam Cohen
When Jim's dog is killed, the other first graders experience with him his natural reactions to death.

Kinda Blue by Ann Grifalconi
Sissy feels lonely and blue until her Uncle Dan cheers her up by explaining that everything, even corn, needs special attention every now and then.

Mrs. Huggins and Her Hen Hannah by Lydia Dabcovich
Mrs. Huggins’ contented relationship with her hen, Hannah, comes to an unfortunate end but is reborn in an unexpected way.

**My Grandfather’s Hat** by Melanie Scheller
A boy recalls his special relationship with his grandfather by playing with his grandfather’s old hat.

**Nana Upstairs and Nana Downstairs** by Tomie DePaola
Every Sunday four-year-old Tommy’s family goes to visit his grandparents. His grandmother is always busy downstairs, but his great-grandmother is always to be found in bed upstairs. Tommy is desolate when his upstairs nana dies, but his mother comforts him by explaining that “she will come back in your memory whenever you think about her.”

**Nannie’s Moon: a children’s book** by Janice Daugharty
Young girl learns from her grandmother about the natural cycles of life and death.

**The Next Place** by Warren Hanson
An inspirational journey of light and hope to a place where earthly hurts are left behind. An uncomplicated journey of awe and wonder to a destination without barriers.

**On Call Back Mountain** by Eve Bunting
Ben and Joe are thrilled when Bosco, the fire watchmen, comes back for the summer. They enjoy reading with Bosco and listening to his music. When Bosco heads to the tower, Ben and Joe say good-bye to him every night with their lantern. After Bosco dies, the two brothers encounter a lone wolf on the spot where they had signaled their friend up on the mountain tower.

**Saying Goodbye to Daddy** by Judith Vigna
Emotions of confusion, resentment, grief, and fear are highlighted after Clare’s father is killed suddenly in a car accident. Clare’s mother and grandfather, themselves grief-stricken, help her through the funeral and her sorrow.

**Saying Goodbye to Lulu** by Corinne Demas and Ard Hoyt
A young girl deals with the death of her dog.

**Sophie** by Mem Fox
This is a book about aging. As Sophie grows bigger and her grandfather gets smaller, they continue to love each other very much.

**Tear Soup: A Recipe for Healing after Loss** by Pat Schwiebert and Chuck DeKlyen
Grandy deals with the first big loss in her life.

**The Tenth Good Thing About Barney** by Judith Viorst
In an attempt to overcome his grief, a boy tries to think of the ten best things about his dead cat.

**Too Far Away to Touch** by Leslea Newman
Zoe has an especially close relationship with her uncle, Leonard, who is now sick. Following a visit to the planetarium, he explains to her that when he dies, he will be like the stars: too far away to touch.

**Up in Heaven** by Emma Chichester Clark
Arthur’s dog Daisy dies and goes to dog heaven. Arthur learns to deal with his loss.

What's Heaven? by Maria Shriver
This is the story of Kate, a little girl whose great-grandma has just died. She seeks answers, and her mother helps her learn about Heaven. The childlike and thought-provoking questions in this book are real, coming from Maria Shriver's own children, nieces and nephews when her grandmother, Rose Fitzgerald Kennedy, passed away.

Where Do People Go When They Die? by Mindy Avra Portnoy
An explanation of death at a child's level in the Jewish faith.

When Dinosaurs Die: A Guide to Understanding Death by Laurie Krasny Brown and Marc Brown
Explains in simple language the feelings people may have regarding the death of a loved one.

When Someone Very Special Dies: Children Can Learn to Cope with Grief by Marge Heegaard
A practical format for allowing children to understand the concept of death and develop coping skills for life.

When Something Terrible Happens: Children Learn to Cope with Grief by Marge Heegaard
Creates ways for children to explore the fright, confusion, and insecurity caused by traumatic events in their lives.

You Hold Me and I'll Hold You by Jo Carson
When a great aunt dies, a young child finds comfort in being held and in holding her father. Words and pictures express both worry and comfort with heart-felt simplicity. This book will help explain funerals for younger children.

Fiction

The Black Dog Who Went Into the Woods by Edith Thacher Hurd
The various members of a family react to the death of their dog.

Blue Eyes Better by Ruth Wallace-Brodeur
When her older brother is killed in an accident, ten-year-old Tessa and her parents find it difficult to overcome their grief and return to living normally.

Cat Heaven by Cynthia Rylant
God created Cat Heaven, with fields of sweet grass where cats can play, kitty-toys for them to enjoy, and angels to rub their noses and ears.

Cousins by Virginia Hamilton
Concerned that her grandmother may die, Cammy is unprepared for the accidental death of another relative.

Daddy's Chair by Sandy Lanton
When Michael's father dies, his family sits shiva; observing the Jewish week of mourning and remembering the good things about him.

The Day Chubby Became Charles by Achim Broger
Afraid that her grandmother might be dying, Julia discovers a new friend with whom she can talk about her fears.

**Dear Napoleon, I Know You’re Dead, But...** by Elvira Woodruff
Marty receives a surprising reply when he writes a letter describing his spirited but sick grandfather to Napoleon Bonaparte.

**Earthshine** by Theresa Nelson
Slim watches over her father, a disarmingly charismatic man, as his struggle with AIDS reaches its climax.

**Emma Says Goodbye: A Child’s Guide to Bereavement** by Carolyn Nystrom
Coming to terms with the death of someone close is hard. But Emma and her family have time to work through their hurt. This story explains what is happening to Aunt Sue as her illness progresses and how Emma, her family, and Aunt Sue herself react.

**Eye of the Wolf** by Daniel Pennac
An Alaskan wolf and an African boy, meeting at a zoo in “The Other World,” read in one another’s eye the hardships each has faced, and their understanding helps to bring healing to them both.

**Flip-Flop Girl** by Katherine Peterson
After their father dies, nine-year-old Vinnie, her mother, and her younger brother, mute since the funeral, move to a small town where Vinnie meets Lupe, a tall, confident, yet odd girl who has also suffered great tragedy.

**Fox Song** by Joseph Bruchac
After the death of her Indian great-grandmother, Jamie remembers the many special things the old woman shared with her about the natural world.

**The Friends** by Kazumi Yumoto
Curious about death, three sixth-grade boys decide to spy on an old man waiting for him to die, but they end up becoming his friends.

**Frog and the Birdsong** by Max Velthuijs
When Frog finds a blackbird lying still on the ground, his friend Pig thinks the bird is asleep, Goose thinks he is ill, but Hare knows the bird is dead. Together the animals bury the small bird, learning to grieve but also to keep living.

**Goodbye Max** by Holly Keller
Ben's dog Max is old and sick. One day Ben goes to school and Max dies. With the help of his friend, Ben is able to remember the fun times with Max.

**Grandad Bill’s Song** by Jane Yolen
After Grandad Bill dies, everyone in the family remembers him differently. But reminiscences do nothing to help a young boy cope with his loss, until he recalls his own feelings on the day his grandfather died—and his memories of a best friend who was much beloved indeed.

**Hang Tough, Paul Mather** by Alfred Slote
Twelve-year-old Paul Mather, hospitalized with leukemia, sneaks out to pitch a Little League game, doing very well until he gets into a collision and is returned to the hospital. A sympathetic doctor helps him participate in another game even as his condition worsens.
The Happy Funeral by Eve Bunting
Laura is a young Chinese-American girl who attends the "happy funeral" of her grandfather. Laura remembers the happy times she shared with her grandfather. Laura realizes that the funeral is happy for her grandfather, as he had lived a good life and was happy to go.

How Do I Feel About When People Die? by Sarah Levette
This book encourages children to explore their feelings about the personal issues that may affect them. This book joins a group of friends as they talk about how they cope with the death of loved ones of all ages.

How to Live Forever by Colin Thompson
Every night for two years Peter searches in the library for the lost book on how to live forever; when he finds it, he makes an important decision.

I Had a Friend Named Peter by Janice Cohn
When Betsy learns about the death of a friend, her parents and kindergarten teacher answer questions about dying, funerals, and the burial process.

Lifetimes by Bryan Mellonie and Robert Ingpen
A pet, a friend, or a relative dies, and it must be explained to a child. This sensitive book is a useful tool in explaining to children that death is a part of life and that, eventually, all living things reach the end of their own special lifetimes.

Loving Ben by Elizabeth Laird
Anna’s teen years bring maturity and fulfillment as she experiences the birth and death of a loved and loving hydrocephalic brother, changing ideas about character in both boyfriends and girlfriends, and working with a child with Down's syndrome.

Molly's Rosebush by Janice Cohn
When Molly’s mother miscarries, Grandma compares a miscarriage to events in nature; not every robin's egg hatches and not every rosebud blooms. Through open communication, Molly and her parents work through their grief and look forward to the beautiful blossoms their newly planted rosebush will yield.

Mustard by Charlotte Towner Graeber
Eight-year-old Alex and his family try to come to terms with the old age and death of their beloved cat.

Pearl's Marigolds for Grandpa by Jane Breskin Zalben
When Pearl's Grandpa dies, she wonders how she’ll get along without him. Who will send her marigold seeds in the spring? During this difficult time, Pearl struggles to get through her daily routine and tries to remember her grandfather. Finally Pearl discovers that she's able to keep him alive in the simplest of ways—by bringing life to marigolds planted in his memory.

The Saddest Time by Norma Simon
Three short stories on the deaths of an uncle, a school friend, and a grandmother. Although these stories mention events leading to each death and some shared moments with this person, children do not learn how to talk to someone who is dying, why the death is so strongly felt, or what the long-term coping process is really like for family and friends.

Some of the Pieces by Melissa Madenski
A year after the death of the father, two children and their mother try to come to terms with their loss.

Stacy Had a Little Sister by Wendie C. Old
Stacy has mixed feelings about her new sister, Ashley, but when the baby dies of sudden infant death syndrome, Stacy is sad and misses her.

**Sun and Spoon** by Kevin Henkes
After the death of his grandmother, ten-year-old Spoon observes the changes in his grandfather and tries to find the perfect artifact to preserve his memories of her.

**Unbroken** by Jessie Haas
Following her mother's death in the early 1900s, thirteen-year-old Harry lives on Aunt Sarah's farm where an accident with her spirited colt leaves her a changed young woman.

**Walk Two Moons** by Sharon Creech
After her mother leaves home suddenly, thirteen-year-old Sal and her grandparents take a car trip retracing her mother's route. Along the way, Sal recounts the story of her friend Phoebe, whose mother also left.

**Water Bugs and Dragonflies: Explaining Death to Young Children** by Doris Stickney
After a water bug suddenly leaves her pond and is transformed into a dragonfly, her friends' questions about such departures are like those children ask when someone dies.

**When Someone Dies** by Sharon Greenlee
This book explores all the feelings one goes through when someone dies; from anger to sadness, and with simple analogies, tries to relate them as a natural part of life. The illustrations depicting scenes in nature that give us joy seem somewhat dated, but are meant to validate life and death as a natural cycle.

**Nonfiction**

**DeShawn Days** by Tony Medina
This is a story crafted by loving memory in heartfelt poetry, as soft as a lullaby and as tough as the boyz in the 'hood. Ten-year-old DeShawn deals with the death of his grandmother in an inner-city neighborhood that buzzes with life.

**The Final Mystery** by Stanley Klein
Explores the meaning of death, how people of different times, regions, and religions have coped with it, and the progress and effects of the war waged against it by researchers, physicians, and surgeons.

**The Five People You Meet in Heaven**, by Mitch Albom
One by one, from childhood to soldier to old age, Eddie's five people revisit their connections to him on earth, illuminating the mysteries of his meaningless life, and revealing the haunting secret behind the eternal question: Why was I here?

**Good Answers to Tough Questions About Death** by Joy Wilt Berry
A broad ranging book written to help children understand the many issues surrounding death.

**Help Me Say Goodbye: Activities for Helping Kids Cope when a Special Person Dies** by Janis Silverman
An art therapy and activity book for children coping with death. Children are encouraged to express in pictures what they are often incapable of expressing in words.

**Holding on to Hope** by Nancy Guthrie
Guthrie shuns platitudes and easy answers and deals head-on with issues of suffering and loss encountered when she lost her infant daughter, Hope.

**How It Feels When a Parent Dies** by Jill Krementz
Eighteen young people ranging in age from seven to sixteen discuss the questions, fears, and bereavement they experienced when one of their parents died.

**I Found a Dead Bird: The Kid's Guide to the Cycle of Life and Death** by Jan Thornhill
The death of a bird is just the start of this book dealing with the life cycle.

**The Invisible String** by Patrice Karst
Specifically written to address children's fear of being apart from the ones they love, this book delivers a particularly compelling message in today's uncertain times that though we may be separated from the ones we care for, love is the unending connection that binds us all.

**The Kids' Book About Death and Dying, by and for Kids** by E. E. Rofes (Ed.)
Fourteen children offer facts and advice to give young readers a better understanding of death.

**The Last Lecture**, by Randy Pausch
Pausch was given a terminal diagnosis of pancreatic cancer. After receiving this diagnosis, he gave an upbeat lecture titled *The Last Lecture: Really Achieving Your Childhood Dreams*.

**Let's Talk about When a Parent Dies** by Elizabeth Weitzman
This book emphasizes the importance of love in helping one through traumatic times in life, as well as the initial shock, self-blame, fear of losing other loved ones, sharing feelings, and eventual adjustment. It also provides advice on surviving the death of a parent and suggests what feelings and behaviors to expect from others.

**Life and Death** by Herbert S. Zim
Discusses the physical facts, customs, and attitudes surrounding human life and death.

**Living With Death** by Osborn Segerberg
Explores mankind's attitudes towards death throughout history, implications of modern technology on when and how we die, acceptance of death, treatment of the dying and the dead, and ways the living cope with death.

**Locomotion** by Jacqueline Woodson
In a series of poems, eleven-year-old Lonnie writes about his life after the death of his parents, separated from his younger sister, living in a foster home, and finding his poetic voice at school.

**Mrs. Hunter's Happy Death**, by John Fanestil
This is Tuesdays with Morrie with a historical twist. This book focuses on lessons on living from people preparing to die. The chapters of this book progress from relatively simple deaths, such as the loss of a pet or the anticipated death of an aged grandparent, to more complex deaths, such as the loss of a sister and a mother to AIDS or the death of an abusive father.

**No New Baby** by Marilyn Gryte
After her unborn sibling dies, a young child tells how she feels about the baby's death. Her grandma explains you're not to blame, we don't always have answers, and it's OK to ask questions.

**Part of Me Died Too** by Virginia Fry
Eleven true stories about young people who experienced the loss of family members or friends. The chapters progress from relatively simple deaths, such as the loss of a pet or the anticipated death of an aged grandparent, to more complex deaths, such as the loss of a sister and a mother to AIDS or the death of an abusive father.

**Remembering Mum** by Ginny Perkins
Mandy died from pneumonia at age 27 leaving two young sons, Sam and Eddy, feeling hurt and confused. This book emphasizes the importance of talking about bereavement and of remembering the people who have passed away. The book reminds readers of the need to express grief in a society that all too often sees death as a taboo subject.

**Sad Isn't Bad: A Good-Grief Guidebook for Kids Dealing with Loss** by Michaelene Mundy
This book helps comfort children facing the worst and hardest kind of reality, telling children what they need to know after a loss—that the world is still safe, life is good, and hurting hearts do mend.

**Sadako and the Thousand Paper Cranes** by Eleanor Coerr
Based on the true story of a young Japanese girl who contracts leukemia as a result of the atom bomb that was dropped on Hiroshima, the story follows Sadako as a healthy schoolgirl winning relay races, through her diagnosis with the atom bomb sickness, to her long stay in the hospital. It is in the hospital that she first begins making origami cranes to pass the time. Her ultimate goal is to make 1000, but she dies with only 644 completed. Sadako's classmates finish making the remaining cranes, and all 1000 are buried with her.

**Silvie's Life** by Marianne Rogoff
This book chronicles a tortured parenthood during the birth and brief life of a severely brain-damaged female infant, Silvie.

**Tuesdays With Morrie**, by Mitch Albom
This is a magical chronicle of a young man and an old man's time together, through which Mitch shares Morrie's lasting gift with the world: lessons in how to live.

**Walking Taylor Home**, by Brian Schrauger
This is the heartbreaking story of a father learning to let go of his young son who was diagnosed with cancer.

**When a Pet Dies** by Fred Rogers
The affable star of Mister Rogers' Neighborhood helps children share feelings of loss, frustration, sadness, and loneliness while offering reassurance that grieving is a natural, healing thing to do.

**When People Die** by Joanne Bernstein
Explains in simple terms the reasons for death, theories on afterlife, burial practices, grief, and the naturalness of death in the chain of life.

**Where's Jess?** by Joy Johnson
A small boy's sibling dies and he notices she is gone. The parents tell him what death is about and how it is all right to remember and talk about Jess.
PALLIATIVE CARE BOOKLIST FOR YOUNG ADULTS

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This booklist is provided as an inventory of published books with palliative care themes that may be considered for clinical use; it is not a formal recommendation.

About David by Susan Beth Pfeffer
When her close friend since childhood murders his adoptive parents and kills himself, 17-year-old Lynn is haunted by the tragedy.

The Afterlife by Gary Soto
Chuy is a 17-year-old boy, born in Mexico and raised in Fresno, California. Although he is tragically murdered in the bathroom of a night club, his sudden death brings about many revelations about life, falling in love, and relationships. Average in looks and in life, Chuy narrates his short life and newly acquainted afterlife as he details his experiences, feelings, and what he learns as a ghost.

After The Wreck, I Picked Myself Up, Spread My Wings, and Flew Away by Joyce Carol Oates
Jenna Abbott separates her life into two categories: before the wreck and after the wreck. Before the wreck, she was leading a normal life with her mom in suburban New York. After the wreck, she is alone, desperate to forget what happened that day on the bridge.

At the End of Words by Miriam Stone
In her memoir, Miriam Stone, currently an undergraduate student at Columbia University, tells a powerful story about mothers and daughters and pain and healing. In the form of poetry and diary entries, Stone shares the difficulty of watching her mother die from cancer and her personal struggle to cope with the everyday issues many teenage girls face.

Autobiography of My Dead Brother by Walter Dean Myers
Jesse fills his sketchbook with drawings and portraits of his blood brother, Rise, and his comic strip, Spodi, Roti and Wise, as he makes sense of the complexities of friendship, loyalty, and loss in a neighborhood where drive-bys, vicious gangs, and abusive cops are everyday realities.

Bang by Sharon G Flake
Mann is only thirteen, yet he has already had to deal with more than most go through in a lifetime. His family is still reeling from the tragic shooting death of his little brother, Jason, each person coping with grief in his or her own way.

Because of Winn-Dixie by Kate DiCamillo
Because of Winn-Dixie, a big, ugly, happy dog, 10-year-old Opal learns 10 things about her long-gone mother from her preacher father. Because of Winn-Dixie, Opal makes new friends among the somewhat unusual residents of her new hometown, Naomi, Florida, and Opal begins to find her place in the world and let go of some of the sadness left by her mother's abandonment seven years earlier.
Before I Die by Jenny Downham
Tessa has just months to live. Fighting against hospital visits, endless tests, and drugs with excruciating side effects, Tessa compiles a list. It's her To Do Before I Die list. And number one is Sex. Released from the constraints of “normal” life, Tessa tastes new experiences to make her feel alive while her failing body struggles to keep up.

A Begonia for Miss Applebaum by Paul Zindel
Henry and Zelda are stunned to discover that their favorite teacher, Miss Applebaum, won’t be back at school teaching because she hasn’t very long to live. Henry and Zelda become the Saturday companions of their beloved teacher and her exuberance for learning, having fun, and helping the homeless is contagious.

The Book Thief by Marcus Zusak
Set during World War II in Germany, this is the story of Liesel Meminger, a foster girl living outside of Munich. Liesel scratches out a meager existence for herself by stealing when she encounters something she can’t resist—books.

Bridge To Terabithia by Katherine Paterson
The life of a ten-year-old boy in rural Virginia expands when he becomes friends with a newcomer who subsequently meets an untimely death trying to reach their hideaway, Terabithia, during a storm.

Catalyst by Laurie Halse Anderson
Eighteen-year-old Kate, who sometimes chafes at being a preacher’s daughter, finds herself losing control in her senior year as she faces difficult neighbors, the possibility that she may not be accepted by the college of her choice, and an unexpected death.

Cellular by Ellen Schwartz
When Brendan is diagnosed with leukemia his life is turned upside down. With a smothering family and distant friends, all seems hopeless until he meets Lark, terminally ill yet full of life.

Choices by Deborah Lynn Jacobs
Overcome with guilt over her brother’s death, a teenage girl shifts between multiple universes in an attempt to find one in which he is alive.

Deadline by Chris Crutcher
Ben Wolf has big things planned for his senior year. Had big things planned. Now what he has is some very bad news and only one year left to make his mark on the world.

Durable Goods by Elizabeth Berg
Katie and her sister, Diane, struggle to cope with the burdens of growing up with an abusive father and the recent loss of a mother.

Ellen Foster by Kaye Gibbons
Having suffered abuse and misfortune for much of her life, a young child searches for a better life and finally gets a break in the home of a loving woman with several foster children.

Elsewhere by Gabrielle Zevin and Alison McGehee
Elsewhere is where fifteen-year-old Liz Hall ends up, after she has died. Here Liz will age backward from the day of her death until she becomes a baby again and returns to Earth. But Liz wants to turn sixteen, not fourteen again. She wants to get her driver’s license. She wants to graduate from high school and go to college. And now that she’s dead, Liz is being forced to live a life she doesn’t want with a grandmother.
she has only just met. And it is not going well. How can Liz let go of the only life she has ever known and embrace a new one?

**Escaping Tornado Season** by Julie Williams
With her father dead, her mother run off to heaven knows where, and her twin brother, seven years buried, just a ghost in her memory, Allie settles in with her grandparents for a cold Minnesota winter.

**Esperanza Rising** by Pam Munoz Ryan
Esperanza's expectation that her 13th birthday will be celebrated with all the material pleasures and folk elements of her previous years is shattered when her father is murdered by bandits. Esperanza's mother then decides to join the cook and gardener and their son as they move to the United States and work in California's agricultural industry.

**Gathering Blue** by Lois Lowry
Kira is a girl who has lost both of her parents. The book opens with her mourning her mother. Because of her deformed leg, Kira is now at risk of being killed herself as she can no longer “contribute” to her society. Her unequalled skill with a needle and thread, however, keep her alive and get her close enough to the power of her society to see its secret horrors.

**The Girl Death Left Behind** by Lurlene McDaniel
Numb with grief when an accident kills her entire family, fourteen-year-old Beth suddenly finds herself living with her spoiled cousin, Terri, and trying to make friends at a new school.

**Grief Girl** by Erin Vincent
When a speeding tow truck hits Erin Vincent's parents, her mom dies instantly. Her dad dies one month later after doctors assure Erin and her sister and brother that he's going to make it. The girls are left to raise their baby brother, Trent—and each other.

**The Hanged Man** by Francesca Lia Block
Having stopped eating after the death of her father, seventeen-year-old Laurel feels herself losing control of her life in the hot, magical world of Los Angeles.

**The Heart of a Chief** by Joseph Bruchac
Elderly Auntie and Doda care for Chris Nicola and his little sister with affection and wisdom. Their mother is deceased and their father is away battling alcoholism. The stories and traditions of Chris's people give the boy the courage and conviction to deal with life.

**The Hemingway Tradition** by Kristin Butcher
Shaw grew up with the same skill and passion for writing as his famous author father; they had planned to write a book together. His dad's sudden suicide changed everything. Shaw is stunned to read of his father's homosexuality in his suicide note and shocked to read that his father felt that he could no longer live in the closet. Shaw questions how much of his relationship with his father had been "a lie."

**How It Feels When a Parent Dies** by Jill Krementz
Eighteen young people ranging in age from seven to sixteen discuss the questions, fears, and bereavement they experienced when one of their parents died.

**If I Stay** by Gayle Foreman
Mia has no memory of the accident that changed her life. The last normal moment that Mia can remember is being in the car with her family. Then she is standing outside her body beside their mangled Buick and her parents' corpses, watching herself and her little brother being tended by paramedics.
**Island of the Blue Dolphins** by Scott O’Dell
When she realizes her brother is missing, Karana, a young Indian girl, runs off the boat that is taking her people away from their island. The boat goes off without them, leaving them both permanently stranded. After her brother dies, she learns to survive alone, finding food and shelter and avoiding the threat of seal hunters who come from big ships.

**Joy School** by Elizabeth Berg
Katie, still mourning the death of her much-loved mother, is further upset when she must leave her friends to move with her father to Missouri, but then she meets Jimmy, a handsome, decent, married man, and learns about the joys and pain of first love. (Sequel to *Durable Goods*, but a good stand-alone read).

**Keeper of the Night** by Kimberly Willis Holt
Thirteen-year-old Isabel, a girl living on the island of Guam, and her family try to cope with the suicide of Isabel's mother.

**Kira Kira** by Cynthia Kadohata
Glittering. That's how Katie's sister, Lynn, makes everything seem. Lynn, with her special way of viewing the world, teaches Katie to look beyond tomorrow. When Lynn becomes desperately ill, it is up to Katie to find a way to remind her that there is always something glittering—*ki ra-kira*—in the future.

**Kit's Wilderness** by David Almond
Thirteen-year-old Kit goes to live with his grandfather in the decaying coalmining town of Stoneygate, England, and finds both the old man and the town haunted by spirits of the past.

**The Last Summer of the Death Warriors** by Francisco X. Stork
One is dying of cancer. The other's planning a murder. When Pancho arrives at St. Anthony's Home, he knows his time there will be short: If his plans succeed, he'll soon be arrested for the murder of his sister's killer. But then he's assigned to help D.Q., whose brain cancer has slowed neither his spirit nor his mouth.

**The Lone Sentinel** by J o Dereske
At his father's untimely death, a teenager assumes control of a light tower at the bleak and lonely outpost of the universe—a job he feels capable of handling until the arrival of two teenage girls and a group of aliens.

**A Love Story Starring My Dead Best Friend** by Emily Horner
For months, Cass has heard her best friend, Julia, whisper about a secret project. When Julia dies in a car accident, her drama friends decide to bring the project—a musical called "Totally Sweet Ninja Death Squad"—to fruition. But Cass isn't a drama person. So Cass takes off. In alternating chapters, she spends the first part of summer on a cross-country bike trip and the rest swallowing her pride, and making props.

**Maniac Magee** by Jerry Spinelli
Maniac Magee is a folk story about a very excitable boy. One that can outrun dogs, hit a home run off the best pitcher in the neighborhood, tie a knot no one can undo. "Kid's gotta be a maniac," is what the folks in Two Mills say. It's also the story of how this boy confronts racism in a small town, tries to find a home where there is none, and attempts to soothe the tensions between rival factions on the tough side of town.

**Many Stones** by Carolyn Coman
After her sister Laura is murdered in South Africa, Berry and her estranged father travel there to participate in the dedication of a memorial in her name.
Maroo of the Winter Caves by Ann Turnbull
Maroo, a girl of the late Ice Age, must take charge after her father is killed, and lead her little brother, mother, and aged grandmother to the safety of the winter camp before the first blizzards strike.

Memory by Margaret Mahy
On the fifth anniversary of his older sister's death, nineteen-year-old Jonny Dart, troubled by feelings of guilt and an imperfect memory of the event, goes in search of the only other witness to the fatal accident and, through a chance meeting with a senile old woman, finds a way to free himself of the past.

Missing May by Cynthia Rylant
Twelve-year-old Summer, her classmate Cletus, and her grieving Uncle Ob seek out a small Medium at large in Putnam County, West Virginia, in hopes of reaching Aunt May beyond the grave.

Moonglass by Jessi Kirby
Anna has always known that something was missing in her life: her mother, who walked out into the ocean one night and never came back. When Anna and her father, a professional lifeguard, move to a different California beach after a job promotion, Anna meets people who know all about her parents, their courtship and early marriage, and her mother's death.

A Music I No Longer Heard by Leslie Simon
Contains seventy true stories of men and women who lost one of their parents while they were still in their teens, and describes how the children coped with the loss.

No More Us For You by David Hernandez
Isabel is still reeling from the pain of her boyfriend's tragic death exactly one year ago. Carlos loves red licorice and his friends, and works at a fancy art museum for some extra cash. The two have no connection until they both meet Vanessa, an intriguing new transfer student with a mysterious past. While Vanessa is the link that brings these two very different lives together, will she be the one that can also tear them apart?

November Blues by Sharon M. Draper
When November Nelson loses her boyfriend, Josh, to a pledge stunt gone horribly wrong, she thinks her life can't possibly get any worse. But Josh left something behind that will change November's life forever, and now she's faced with the biggest decision she could ever imagine. How in the world will she tell her mom? And how will Josh's parents take the news?

One of Those Hideous Books Where the Mother Dies by Sonya Sones
Fifteen-year-old Ruby Milliken leaves her best friend, her boyfriend, her aunt, and her mother's grave in Boston and reluctantly flies to Los Angeles to live with her father, a famous movie star who divorced her mother before Ruby was born.

Out of the Dust by Karen Hesse
Billie Jo reveals the grim realities of living during the years of constant dust storms. Billie Jo's silent, windblown father is literally decaying with grief and skin cancer before her very eyes. When she decides to flee the lingering ghosts and dust of her homestead and jump a train west, she discovers a simple but profound truth about herself and her plight.

The Outsiders by S. E. Hinton
Three brothers struggle to stay together after their parent's death. This is the story of their quest for identity among the conflicting values of their adolescent society.
Part of Me Died Too by Virginia Fry
Eleven true stories about young people who experienced the loss of family members or friends. The chapters progress from relatively simple deaths, such as the loss of a pet or the anticipated death of an aged grandparent, to more complex deaths, such as the loss of a sister and a mother to AIDS or the death of an abusive father.

Pedro and Me: Friendship, Loss, and What I Learned by Henry Holt
In graphic art format, this book describes the friendship between two roommates on the MTV show “Real World,” one of whom died of AIDS.

Phoenix Rising by Karen Hesse
Nyle’s life with her grandmother is thrown into chaos the night of the accident at the Cookshire nuclear power plant. Ezra Trent and his mother, refugees from the heart of the accident, take temporary shelter in the back bedroom of Nyle’s house. Nyle doesn’t want to open her heart to Ezra. Too many times she’s let people in, only to have them desert her.

The Pigman by Paul Zindel
When sophomores John and Lorraine played a practical joke a few months ago on a stranger named Angelo Pignati, they had no idea what they were starting. Virtually overnight, almost against their will, the two befriended the lonely old man. But now Mr. Pignati is dead. And for John and Lorraine, the only way to find peace is to write down their friend's story— the story of the Pigman.

Please Ignore Vera Dietz by A.S. King
Vera's spent her whole life secretly in love with her best friend, Charlie Kahn. And over the years she's kept a lot of his secrets. Even after he betrayed her. Even after he ruined everything. So when Charlie dies in dark circumstances, Vera knows a lot more than anyone—the kids at school, his family, even the police. But will she emerge to clear his name? Does she even want to?

Riley Park by Diane Tullson
After a party at Riley Park, Darius and Corbin are attacked. Darius is killed; Corbin is seriously injured. Corbin fights his clouded memory—he can't identify the assailants. He fights his weakened body—he can no longer play hockey. He fights the loss of his friend. But when he gives up the fight, he finds strength in acceptance.

A Ring of Endless Light by Madeleine L'Engle
During the summer her grandfather is dying of leukemia and death seems all around, 15-year-old Vicky finds comfort with the pod of dolphins with which she has been doing research.

The Secret Life of Bees by Sue Monk Kidd
Fourteen-year-old Lily and her companion, Rosaleen, an African-American woman who has cared for Lily since her mother's death ten years earlier, flee their home after Rosaleen is victimized by racist police officers, and find a safe haven in Tiburon, South Carolina at the home of three beekeeping sisters, May, June, and August.

So Shelley by Ty Roth
After stealing Shelly's ashes from her wake at Trinity Catholic High School, the boys set a course for the small Lake Erie Island where Shelly's body had washed ashore and to where she wished to be returned. As they navigate around the obstacles and resist temptations during their odyssey, Keats and Gordon glue together the shattered pieces of Shelly's and their own pasts while attempting to make sense of her tragic and premature end.
Shizuko's Daughter by Kyoko Mori
After her mother's suicide when she is twelve years old, Yuki spends years living with her distant father and his resentful new wife, cut off from her mother's family, and relying on her own inner strength to cope with the tragedy.

A Stone in My Hand by Cathryn Clinton
Eleven-year-old Malaak and her family are touched by the violence in Gaza between Jews and Palestinians when first her father disappears and then her older brother is drawn to the Islamic Jihad.

A Summer To Die by Lois Lowry
Thirteen-year-old Meg envies her sister's beauty and popularity. Her feelings don't make it any easier to cope with Molly's strange illness and eventual death.

Tales of the Madman Underground by John Barnes
For years, Karl's been part of "the Madman Underground"—kids forced to attend group therapy during school. Karl has decided that he is going to get out of the Madman Underground for good. He is going to act-and-be-Normal. But Normal, of course, is relative. Karl has two after-school jobs, one dead father, one seriously unhinged drunk mother . . . and a huge attitude.

Tears of a Tiger by Sharon Draper
The death of high school basketball star Rob Washington in an automobile accident affects the lives of his close friend Andy, who was driving the car, and many others in the school.

Thirteen Reasons Why by Jay Asher
Clay Jensen returns home from school to find a mysterious box with his name on it lying on his porch. Inside he discovers cassette tapes recorded by Hannah Baker—his classmate and crush—who committed suicide two weeks earlier.

A Time for Dancing by Davida Hurwin
Seventeen-year-old best friends Samantha and Juliana tell their stories in alternating chapters after Juliana is diagnosed with cancer.

Toning the Sweep by Angela Johnson
Fourteen-year-old Emily learns the ritual of "toning the sweep," a way of drumming a plow to create a sound that honors the deceased, in this tale of mourning and healing. Emily, her mother, and terminally ill grandmother, Ola, are the three extraordinarily strong females in these stories of grief and hardship that have undoubtedly fostered the inspirational resilience in each of their personalities.

Tuck Everlasting by
10-year-old Winnie Foster is on the run from her stifling and lonely family life when she stumbles upon a young man sipping water from a spring at the base of a giant oak tree. The young man is Jesse Tuck, the youngest member of a family blessed—or cursed—to live forever. While Winnie stays with the Tucks for just a few days, she learns more about their secret and what it really means.

Two Moons in August by Martha Brooks
Kieran, a new boy visiting her small town for the summer, helps Sidonie and her family come together again following the death of Sidonie's mother.

Walk Two Moons by Sharon Creech
Thirteen-year-old Salamanca Tree Hiddle's mother has disappeared. While tracing her steps on a car trip from Ohio to Idaho with her grandparents, Salamanca tells a story to pass the time about a friend named
Phoebe Winterbottom whose mother vanished and who received secret messages after her disappearance.

**Ways to Live Forever** by Sally Nicholls
Sam loves facts. He wants to know about UFOs and horror movies and airships and ghosts and scientists, and how it feels to kiss a girl. And because he has leukemia he wants to know the facts about dying.

**When Dad Killed Mom** by Julius Lester
Jenna and Jeremy knew their parents’ marriage was in trouble. But no one could have predicted what would come next. Now with Mom dead and Dad in jail, Jenna and Jeremy must re-create a family of their own. But each guards a secret that could send their fragile new lives into a tailspin.

**Whirligig** by Paul Fleischman
While traveling to each corner of the country to build a whirligig in memory of the girl whose death he causes when he was trying to commit suicide, sixteen-year-old Brian finds forgiveness and atonement.

**Wintergirls** by Laurie Halse Anderson
Lia and Cassie were best friends, wintergirls frozen in matchstick bodies. But now Cassie is dead and the voice inside Lia’s head keeps telling her to remain in control, stay strong, lose more, and weigh less. If she keeps on going this way—thin, thinner, thinnest—maybe she’ll disappear altogether.
BOOKS FOR ADULTS WITH PALLIATIVE CARE THEMES

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In conjunction with the Madison Public Library; updated 2010.

This booklist is provided as an inventory of published books with palliative care themes that may be considered for clinical use; it is not a formal recommendation.

10. **Final Gifts**: Understanding the Special Awareness, Needs, and Communications of the Dying by Maggie Callanan & Patricia Kelley (1992) - two hospice nurses advance the concept of "nearing death awareness."
11. **Changed by a Child: Companion Notes for Parents of a Child with a Disability** by Barbara Gill.
12. **Finding Hope When a Child Dies** by Sukie Miller - discusses other cultures' approaches to dealing with grief after loss of a child.
13. **Alex: The life of a Child** by Frank DeFord - a father's story of losing his daughter at age 8 to CF.
14. **The Spirit Catches You and You Fall Down** by Anne Fadiman - story of a Hmong child’s illness and the cultural issues involving his medical care.
15. **Sick Girl** by Amy Silverstein - patient account of heart transplant as a young adult.
16. **Death be Not Proud** by John Gunther - a father's memoir of his teenage son who died of a brain tumor.
17. **A Book of James** by Jeannie P. Beggins - journal by parents of an infant who died.
18. **Sick Girl Speaks: Lessons and Ponderings Along the Road to Acceptance** by Tiffany Christensen - patient's autobiography of living with CF and multiple lung transplant.
20. **The Power of the Powerless** by Chris De Vinck - family account of having a disabled family member.
21. **If I Get to Five** by Fred Epstein - physician’s view of pediatric illness.
22. **Losing Malcolm: A Mother's Journey Through Grief** by Carol Henderson.
Items of Interest: In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. **Touching Rainbows—Acknowledging the Child’s Voice in Palliative Care.** To mark World Hospice and Palliative Care Day, which occurred on October 8, 2011, the International Children’s Palliative Care Network launched its new book, *Touching Rainbows—Acknowledging the Child’s Voice in Palliative Care*. The book offers an opportunity to hear the voices of some of the many children whose lives, and those of their families, have been affected by life-threatening conditions.

The children tell their stories with honesty and openness, through stories, poems and pictures. Children and their families from across the world share their experiences, either from the child themselves or, when their own voice cannot be heard, from those who love them, such as their parents, siblings and sometimes their careers.

The stories, told in the child’s own language wherever possible and with an English translation, are an inspiration to us all. It is hoped they will touch and enrich the lives of many, encourage those traveling a similar path, and instill a sense of courage and joy, despite the many challenges and heartaches. These children and their families pass through many storms and dark days, but still aspire to reach out and touch the light and joy of the rainbow.

The Foreword is written by Sister Frances Dominica, the Founder of Helen and Douglas House, and of the modern children’s hospice movement.

Copies of this book can be bought through the ICPCN website, [www.icpcn.org.uk](http://www.icpcn.org.uk)

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2. **Pediatric Palliative Care – film 21 of 50 in the LIFE Before Death documentary series.** This online video about the global crisis in untreated pain and the dramatic life-changing effect palliative care services can deliver to patients and their families around the world. In this short film we discover that the barriers to paediatric palliative care are very complex and children’s pain is often under treated. We learn that providing good care is crucial to the quality of life for the child but that support needs to be extended to the whole family.

“I think that in the paediatric population pain is more frequently under recognized and under treated than it is in the adult population, though the medications are available, sometimes the training for physicians is a little bit inadequate and physicians feel unsure in their ability and concerned about the medications,” reflects Dr Kim Bower (USA).

Joan Marston recounts the story of a young girl with severe pain and with a neuro-degenerative condition being denied the amount of morphine she needed for pain control by a pharmacist who felt she must be an addict until he actually went to the girl’s bedside to see for himself, only to realise how wrong he was.

Hear this and other stories of children’s lives being changed by accessing palliative care. **Featuring:** Dr Kim Bower (USA), Joan Marston (South Africa), Dr Henry Ddungu (Uganda), Jareal Bantilan (Singapore), Jessica, Hendra & Esther (Indonesia)

50 Short Films have also been produced which are being released at a rate of one per week, they are currently available at: [www.youtube.com/lifebeforedeathmovie](http://www.youtube.com/lifebeforedeathmovie).
3. **New Free Booklet: Basic Symptom Control in Paediatric Palliative Care.** The UK children’s palliative care charity ACT (Association for Children’s Palliative Care) has launched a newly revised and extended key resource for all doctors and nurses providing care and support to terminally ill or life-threatened children. The resource, Basic Symptom Control in Paediatric Palliative Care aims to provide doctors and nursing staff with an “all in one” reference tool for symptom management and children’s palliative care medicines.

Basic Symptom Control in Paediatric Palliative Care contains information about how to appropriately treat a wide range of symptoms and contains 28 chapters on the most common symptoms and issues within children’s palliative care. It also includes a comprehensive prescribing formulary to support those prescribing in children’s palliative medicine, covering over 90 medicines. The formulary has been adapted from the Association of Paediatric Palliative Medicine’s master formulary for children’s palliative medicine.

Caring for babies, children, and young people who have a terminal or life-threatening health condition can be very daunting for GPs and paediatricians. Many GPs may only care for one or two children with life-limiting conditions in their entire working life. Basic Symptom Control in Paediatric Palliative Care has been designed to address some of the fears and challenges that these professionals may face.

Basic Symptom Control in Paediatric Palliative Care has been developed and edited by Dr. Satbir Singh Jassal, GP and Medical Director at Rainbows Children’s Hospice, with contributions and peer reviews from 30 leading paediatric and palliative care specialists. The resource has been published by ACT and is funded by the Department of Health. Basic Symptom Control in Paediatric Palliative Care is available free to download at [www.act.org.uk/symptomcontrol](http://www.act.org.uk/symptomcontrol).

4. **Two Additional Free Resources Continue to be Available from ACT (Association for Children’s Palliative Care) in the UK.** A Care Pathway to Support Extubation within a Children’s Palliative Care Framework (56 pages) and a 20-page leaflet, A Parent’s Guide: Making Critical Care Choices for Your Child, are available from ACT’s website [www.act.org.uk/extubation](http://www.act.org.uk/extubation).

5. **Three Pediatric Palliative Care Online Courses Available.** A new course has been added to NHPCO’s Pediatric Palliative Care Online Training Series: Ethics, Decision Making and Advance Care Planning. The series provides instant access to educational resources for pediatric care provider in 10 online educational modules written by leading pediatric palliative/hospice care experts. The Ethics module is the third in the series joining Pediatric Palliative Care Principles and Standards and Pediatric Palliative Care Delivery Models. Each module offers valuable content, case studies and practical examples to help your organization deliver quality care for children with life-threatening conditions and their families. Learn more and access the online modules at [nhpc.org/pediatrics](http://nhpc.org/pediatrics).

6. **Concurrent Care for Children Implementation Toolkit.** On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act (PPACA) into law, enacting a new provision, Section 2302, termed the “Concurrent Care for Children” Requirement (CCCR). Section 2302 requires that every state Medicaid program pay for both curative treatment and hospice services for children under age 21 who qualify. Prior to the enactment of this law, children with life-threatening illness, and their families and care providers, had very few options. Parents in all but a few states were faced with forgoing curative treatments for their children in order for that child to be eligible for hospice services.

The District of Columbia Pediatric Palliative Care Collaborative (DCPPCC) and NHPCO are pleased to provide the Concurrent Care for Children Implementation Toolkit, which details information on the options available to states implementing Section 2302 or are considering expansion of pediatric palliative care.
services to children living with life-limiting or life-threatening conditions. To view and download this free toolkit, visit nhpco.org/pediatrics.

7. Standards of Practice for Pediatric Palliative Care and Hospice Receive AAP Affirmation of Value. As we have reported previously, NHPCO Standards of Practice for Pediatric Palliative Care and Hospice (Standards) have received the American Academy of Pediatrics Affirmation of Value. The Standards are a supplement to the NHPCO Standards of Practice for Hospice Programs and are designed to supplement the existing Standards and to set clinical and organizational precedents for hospice and palliative care programs providing care to infants, children, adolescents, young adults, and their families in the home, hospital, long-term care and respite setting. The Standards establish an important beginning to ensuring that children and their families receive high quality pediatric palliative care and hospice services.

The Standards of Practice for Pediatric Palliative Care and Hospice are available in downloadable format, free-of-charge to NHPCO members and for a nominal price for all others. They can be downloaded from NHPCO online.

8. Calendar of Events. As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, www.nhpco.org/pediatrics. ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics. Please e-mail Christy Torkildson at torkc@sbcglobal.net to have your pediatric palliative care educational offering listed.

Thank You
We appreciate you 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 nhpco.org/pediatrics for further materials and resources of interest.

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