ChiPPS Pediatric Palliative Care Newsletter

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Issue Topic: Help and Healing: Bereavement Perspectives

Welcome to the twenty-third issue of the ChiPPS electronic newsletter. This issue of our e-newsletter offers a PDF collection of articles that explore some issues involving help and healing in relationship to bereavement perspectives. 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 http://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.

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Issue #23: Help and Healing: Bereavement Perspectives

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

**School Pictures**  
Scott Newport  
Evan’s father, Scott, writes about poignant moments in his bereavement that jar him back and forth between the past and his current reality that finds him forever without Evan’s physical presence.  

**Absent**  
Scott Newport  
A father’s poem reflecting upon being absent at his son’s time of death.

**This Is Not a Club You Would Join**  
Ann-Patrice Foley, LMSW  
Ann-Patrice is a pediatric social worker who provides insights from bereaved parents she has supported. She offers perspectives on questions that arise in the parent bereavement experience – “How long will the grief last?” and “How do we get through this as a couple?” Her article provides practical suggestions for how to walk with parents who are in a “club” that no one asked to join.

**We Will Always Be Parents of a Baby: Parents’ Search for Meaning, Connection, and Hope after a Baby Dies**  
Jane Fleming, MPM  
Support groups provide a special setting for special losses. From her work as a grief counselor, Jane writes about her experience facilitating an infant loss support group with three couples.

**Loss in International Adoption: Grief Remembered**  
Trish Benton, LSW, CT  
Trish describes her experiences as an expectant adoptive mother whose baby is tragically injured and the adoptive process is closed. The grief she and her husband experienced went unacknowledged by the adoption community; instead, they quickly moved to replace their longed for baby. Trish is later relieved to learn that the adoption community now has resources in place to support parents who encounter this type of loss.

**When Life’s Novel Is Cut Short**  
Patricia Loder, The Compassionate Friends  
The Compassionate Friends Executive Director, Patricia Loder, writes about the experience of day by day survival and coping after the death of a child. Daily she encounters parents mourning the loss of their child, a forever loss in all too short lives.

**Complicated Bereavement and the Power of Forgiveness**  
Karen Painter, LMHC  
The motto, “no regrets” is one that Karen regularly shares with the families she supports as a counselor. She writes about how bereavement can be further complicated for parents and families when their loss is compounded by a history of previous losses and trauma. Karen sets forth two case examples that speak to these complexities and suggests clinical approaches when a family is experiencing multiple losses.
When a Parent Is Dying  
Liz Sumner, RN, BSN  
Children deserve support and consideration when an important person in their life is dying and they are grieving. Liz provides data on the number of children impacted by the illness and death of a significant person in their lives. She offers considerations for adult-focused hospice programs on how to support these children and parents as they attempt to live as fully as possible in their changing condition and parenting role.

Let's Change the Way We Grieve, One Child at a Time  
Kelly J. Rhoades, PhD  
This article focuses on what grieving children need from the adults in their lives when someone they love is dying. Not-so-helpful approaches to support are discussed and alternative adult responses are offered on how to best support a grieving child at home, in the classroom, and in the larger community setting.

Benefits of Bereavement Follow-up Phone Calls  
Jill K. Wilke, BSN, RN, and Rana K. Limbo, PhD, RN, PMHCNS-BC  
Jill and Rana provide a history and overview of the Resolve Through Sharing (RTS) model of care. The model focuses on providers communicating to families that they are cared about, especially at difficult times (e.g., anniversaries). Jill and Rana also provide examples of dialogue to be used when providing follow up calls to bereaved families.

Compilation of Grief/Bereavement Resources for Healthcare Professionals and/or Families  
Reader's Corner: Quilly's Sideways Grief: A Story-Based Curriculum  
Kelly J. Rhoades, PhD  
Reader's Corner: Peace of mind and sense of purpose as core existential issues among parents of children with cancer  
Suzanne Toce, MD  
Reader's Corner: A Gift of Time: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief  
Amy Kuebelbeck and Deborah L. Davis, PhD  
Items of Interest
Leaving out the back door for work, I had to shuffle through three pairs of shoes, a pink down jacket, a school backpack, and a large unzipped bag full of Noah’s lacrosse gear to reach the door. Stretching for the light switch my eye caught a picture of my two boys, Noah and Evan. They were both looking at each other head on. Noah has swim goggles pasted up on his forehead, obviously taken in the summer.

Immediately I was caught off guard with the realization of how Noah has changed so much in the last year. It reminded me of my high school graduation picture hanging at my folk’s house, curly hair and all. Every time I see it I can’t believe how long my hair was. Evan on the other hand looked the same as the year before.

The same as I remember him before he died. The one picture I can’t get out of my head is the one that captures him curled up in his crib, dead. Just over a year ago, about an hour after the night nurse left, I ran to the sound of the beeping medical monitors. Just minutes before he had been playing with a Christmas globe that lit up the ceiling and filled the mini ICU with traditional holiday songs. My wife, Penni, came running too. The ventilator was still pulsing away. But Evan was gone.

As the months have dragged on I find myself dealing with a life filled with changing emotions. It often runs like a continuous slideshow – sometimes stopping, other times paused so the viewer can take a longer look. So far it seems to have continual re-runs. The first emotion was a stabbing guilt, then sadness found a way to take hold, and anger took awhile to show up. He comes often lately.

Even failure has its way with me, too. I don’t know if that is an emotion but it sure is a state of mind. I call it the black spot, centered on the back of my head like a target. Not the kind of target folks aim for but the kind of target that says, “Should I take a shot at talking to him?”

Now if you were to ask Penni or my Noah, I am not sure what they would say. You see, we don’t talk about it much. One of the biggest revelations to me during these past few months is that everyone grieves differently. Their picture I title the “three ring circus.” They are going all the time. If it’s not the three or four cousins over for the weekend, it’s going to church, then shopping, then to a movie, and even back to church again.

I have noticed that I do kinda the same thing as Penni and Noah at times by hoping there is enough work so I can be gone on Saturdays. I also cry a lot, most of the time when I am alone. I find writing poems helps reveal the depth of my sorrow. Each of us are taking on grief one frame at a time, never the same in unison, just running at the same time projecting our lives on the screen of life.
So I guess we have to know that if we take a picture of a person who is grieving at one particular moment, it doesn’t mean the next time you see them it will be the same.

Even Linda, who has been my trusted social worker from our Hospice Palliative team doesn’t always get it. She knows it in her heart and head but – well, let me put it this way: I once asked her, “Hey Linda, how you do this, I mean dealing with all these families who are losing or have lost a child?”

She looked at me and slowly responded, “Scott, it wasn’t my child who died.”

But what I loved best was when one day after Linda and I tangled with grief in my den, she said, “Scott, if when I go, I can leave you with just a speck of hope, I am happy.”

“Oh my gosh,” I screamed in my head. I sat there on the couch for a moment and searched for the words to say. I scrambled in my mind to say what I knew would rock her a bit. “Linda,” I said. “If only you knew, you have given me way more than hope. You have given me and my family life.”

I wasn’t sure how to explain it to her but it kinda goes back to the picture thing. She understood that every time she came to see us that she allowed the image at that moment to expose and develop before she said a word. Not too many will do that. And she knows that her job is not to take away the grief but to walk with me along my journey, the journey where the picture is always changing.

Anyway, maybe next time I talk with Linda about the grief journey we can talk about taking that first small step back into Evan’s little room and me being okay with that.
ABSENT
Scott Newport

To those who were not there
To say good bye with a final kiss
To feel the last breath escape
Upon your cheek soaked with tears

To those like me-
Who suffer the loss of a child
The guilt of not
Being there in the end

A helpless place we rest
Now in the arms of Jesus
Fighting the pain in vain
Finding a new forever

We now grasp the memory
One, deep sigh at a time
Barricading our precious thoughts
When our soul starts to flee

Alone we are not
Weak and mute we hide
From each other
I know, that’s me.
This is not a club you would join…

These were the words of my preceptor, a number of years ago, during my internship at Angela Hospice in Livonia, Michigan.

These words have stuck with me. As I continue in her legacy and become increasingly involved with parents whose child or children have died, I remember these words: “This is not a club you would join.”

“But,” I often think, “without having chosen to, so many parents are in the club anyway, so what now?”

When we lose our grandparents or our parents, we lose a piece of our past. We can be sad and grieve such a loss, but we expect it to happen. When we lose our spouse, partner, sibling or close friend, we lose a piece of our present. From the time we understand death, and the finality of it, we know that these losses are a real possibility. However, when we lose a child, we lose our future.

This is not the kind of loss we “expect” to happen. Oh, we know it happens. We hear about it. Pregnant moms miscarry or have still-born babies. Babies have abnormalities, sometimes genetic, sometimes not. Children get sick. Children have accidents. Children are in accidents. Children are killed. Children take their lives.

But this happens to others. God forbid. Not us, right?

Your child has died. Now what? What is a parent to do?

Parents can spend a life-time trying to make sense of this type of loss. Many times, in the course of working with parents whose child is dying (or has died) I have heard parents say, “I’m trying to make sense out of a senseless situation; I just can’t wrap my head around it.”

While the death of any loved one, particularly a child, will always be a unique and highly individual experience, there are commonalities in the grief process. The grief process for bereaved parents is both intense and lengthy. It is critical to recognize the multiple facets and layers of parental grief that make it different from other kinds of grief. Literature that states that “normal grief lasts six months to one year,” is found to be inadequate and false when applied to parental grief. Parents struggle to retain and preserve memories from the past, while letting go of the dreams and goals for the future with their child. Parents tell us and remind us… this isn’t a loss you “get over.” You have to learn how to navigate through your life with this loss.
So how long does this grief last?

Our logic tells us that grief will decline steadily over time. In reality, the experience is not so much a healing as a gradual acceptance of a pain that fluctuates in intensity and changes in complexity over time, but does not disappear. Parents tell us that, in most cases, such grief may be more intense after one year has passed. They say there are many factors that make this a reality. During the first year, they have their “guard up.” Parents often try to mentally prepare for their experiences without their child. The child’s first birthday, holidays, back to school, the anniversary of the death. Then, as time continues, parents state they let their “guard” down a little, and their family and friends are less vigilant, too. Parents voice, "It has been *that much longer* since I held my child, felt my child, heard my child." They miss their child’s scent, and long for anything that will bring back those memories.

The extended family and friends, who may have been acutely aware during the first year of grief and were often protective of the parents and sensitive to their loss, often transition to a new message to the bereaved parents. In verbal or non-verbal ways, these well-meaning loved ones convey that it is now time to move on, and make changes that bereaved parents are often not ready to make.

Parents state that they are fearful that people will forget their child. They express the fear that even as parents, they too will forget certain aspects of their precious child. They are afraid of forgetting some of the details and the memories that are important to them. Numerous parents tell me they thought they were going crazy, because the second year hurt more not less. Additionally, if the parents become pregnant with a new child, the community that serves them often believes the parents should not continue to feel sad. Family, friends, and co-workers do not understand why parents continue to grieve about a child who has died, since they now have a new child to look forward to. People often assume that the arrival of a new child will take away the pain of the child who died. Parents repeatedly report that this is not their truth.

So how long does parental grief last? Talk to any parent, of any age, who has had a child die. I recently met a woman in her nineties, who was dying in our Angela Hospice Care Center, and she told me that she had two children pre-decease her. One who died at childbirth; one died when the child was a teenager.

I asked her this question: “How long did your grief last?”

She replied without hesitation…"It still exists."

She went on to explain, “There are good days and there are bad.”

So the answer to the question? It lasts as long as it lasts.

Grief and gender…is there a difference?

Parental bereavement can place stress on a marital or parental relationship. Suffering a common loss may not draw partners together. Each parent has experienced a severe dismemberment of self. They
may feel incapacitated and unable to help each other or fulfill parental roles. Mothers and fathers tend to grieve differently, and are often out of sync with one another in their grief. There is no “right” or “wrong” way to grieve. It is important to learn about and recognize some of the gender differences, so they can be dealt with—allowing each parent to have a better understanding of themselves and each other. It is in recognizing, understanding, validating, and allowing the differences—where healing of the parental relationship can occur.

**Standing in the presence of grief.**

So how do we help grieving parents? My suggestion is to listen. It is as simple, and as complex, as that.

Listen. Listen. Listen. Stand in the presence of their grief. For however long it takes. Don’t put parameters and time-frames to their grief. Be still. Don’t be quick to try to “fix” them.

The parents are the ones to teach us. Assume nothing. Let them tell you what they are experiencing, and what they need. Normalize their feelings, thoughts, emotions and concerns. Validate them and invite them to keep coming back. Create a safe place for them to process grief. Allow them to tell their story, over and over if need be. It is often in the telling and retelling of their story that healing takes place. Listen as they relive memories. In an individual, couple, family, or group therapy setting, let them know they are not alone in their thinking and feeling.

Remind them to be gentle on themselves, as they continue on their grief journey. Assist them in creating a “back up plan” for themselves, when life is overwhelming and becomes too much to handle. Give them permission to do things differently. It is important to allow grieving parents to share their experience, strength, and hope. Stand in the presence of their grief.

**Turning pain into passion…**

So, the members of this club… What can they teach us? I’ll tell you what I’ve seen…

Parents change after going through the death of a child in deep and powerful ways. Bereaved parents are compelled to change what they do, how they live…into something meaningful and genuine. I have discovered that many bereaved parents turn their pain into passion. They are transformed individuals, as a result of their child and their experience. Bereaved parents advocate for research. They raise funds and awareness, to find cures for disease and illnesses. They help create legislative change. They support and promote causes. They cannot be superficial. They help other parents and families, and are deeply compassionate and empathetic people. They have riches and values. There is much they can teach us.
Twenty years ago I worked as a hospital chaplain. The most significant memory I hold from this work was one day being paged to offer the Sacrament of Baptism to a baby who was stillborn. I hold in my memory the parents, their faces a soft blur, shocked by the request they were making, together holding a tiny, motionless child. This was not in the plan; “Our baby was supposed to come home with us.” The Sacrament was subdued by the fact that this child would not be actively joining a church community, but would receive the cleansing of original sin through the ritual of baptism, which was significant to her parents. Its’ meaning was nestled in the folds of their faith and provided some buoyancy in the waters of their new grief. It was the first step for them to find an anchor of personal meaning, and, though I didn’t follow them on their journey of healing from this loss, my current work as a grief counselor for parents who have lost a child was informed by that late afternoon visit to their hospital room.

*Be present with these parents in their truth* was a mantra that helped me bear witness to their pain; in the years that I’ve worked with parents who have lost babies and older children, what I know about supporting someone in their loss is *presence*. Whether it is my presence at a stillbirth baptism or presence in a bereavement visit at the home of a mother whose child died after so much hope for remission of a cancer, or presence in a support group for loss of an older child, it is what I can offer parents as they attempt to find support, identify personal beliefs, and seek meaning in challenging life situations. This seeking, at times, may look like a journey of survival fueled by innate resilience and a spirit of hope; three, six, twelve months later - inching toward healing, with hope and trust; sliding backward, numb and frightened….then forward again as footing is found and the waters begin to recede.

I coordinate the bereavement program for the Stepping Stones Palliative Care Program at Providence Hospice of Seattle. In 2010, I offered a support group for three couples who had each lost a baby in the previous twelve months. I had been offering grief counseling to Liz and John after their daughter, Teresa, died on this service. During one counseling session, Liz stated that she and John and another bereaved couple, Cate and Thomas, had been meeting informally to support each other and were interested in participating in a facilitated infant loss group but there wasn’t one offered in the community – could we form one? I invited another couple, Alison and Dennis, who were interested in group support, and we began meeting for the next year, the parents sharing the language of loss and offering one another the hope of healing.
Cate and Thomas:
Having a baby and suddenly not

Cate and Thomas’ son Tommy was nine weeks old when he died within a day of experiencing an intestinal blockage. He went from a healthy boy to dying in the hospital. Cate said, “I lost my identity literally overnight – I was a mom of a sweet two-and-a-half-month old, with a personality and a smile, to suddenly becoming a bereaved mom – you know there’s no other name for us. I was in shock.” Having a baby and suddenly not; the loss of identity was confusing – Cate and Thomas went through the motions of planning a memorial service to honor Tommy’s brief life, then flew to Hawaii to let the salt of their tears mingle with the salty ocean air. Returning home, their jobs and lives felt empty and their emotions ran from resentment to despair.

How do you resettle into your place in your community? Cate and Thomas’ close friends were just like them; young, successful working couples starting their families. Friends either had babies or were expecting babies. Coming home without Tommy was awkward, isolating – surreal.

Liz and John:
Unexpected, limited time with their baby

There were no indications that Teresa would be born with a genetic disorder that would limit her life. This wasn’t discovered until she was four weeks old when Liz realized that Teresa wasn’t moving her legs. The next few weeks were frantically spent at Children’s Hospital, and a diagnosis of Spinal Muscular Atrophy (SMA), was reached. After multiple consultations with the medical staff and the realization that Teresa’s loss of muscle control was progressing rapidly and would continue until she would be unable to breathe on her own, Liz and John elected pediatric palliative home care through Stepping Stones, and at 6 weeks of age, Teresa came home. She lived for 10 days, receiving her mother’s milk through a feeding tube and was surrounded by her loving family and the sounds and smells of home.

The family has photos of Teresa all around the house and Liz and John keep her memory fresh for their other daughter, Caroline, with stories of “Angel Teresa.” They wonder about the time when three-year-old Caroline will not have personal memories of Teresa. Liz, restless to “do” something to change another family’s possible experience, has become an outspoken advocate for SMA education and prenatal testing for this genetic disorder: “It’s a simple blood test.” She has been invited to lobby in Washington, DC, and to speak at pediatric palliative care education symposiums.

Alison and Dennis:
Expected, limited time with their baby

Alison and Dennis knew there might be cause for concern when Alison was pregnant with Rebecca – prenatal ultrasounds revealed she had 6 digits on one hand and her ventricles were dilated. She was born with a still-undiagnosed genetic disorder and lived in the NICU nearly all of her five months of life (she briefly came home for a few weeks).

A few months after Rebecca’s death, Alison went back to her medical practice. Working a three-day work week, she felt she needed to do something meaningful with the days she should have been with Rebecca. Alison wanted to be around children and, in some personal way, ease the hospital experience
(which she knew so well) of other families. She applied for and completed volunteer training with Children’s Hospital and is there one day a week, spending time with children while their parents take a break or a nap.

Alison and Dennis wanted to do something as a couple, and chose to walk in a fundraiser for cancer awareness. Dennis works at a large corporation. He considers the work “lacking meaning” and wonders how he can somehow give back, help others, honor Rebecca’s short life – organize a bicycle ride? Create a gift-giving program at his workplace? He continues to search for this niche.

**Experts on pediatric grief and loss**

“What is my new role?” Cate asks. “I’m considered the ‘expert’ on loss of a baby,” she answers the question herself. “I have a friend who is having prenatal complications and whose baby may not survive birth – she looks to me to be the expert as I have been through so much – it’s a weird role to have but one I feel I need to step up to.”

Each parent struggles with what to do with the experience of losing their child, and each identifies how unique this process is. Cate and Thomas became the experts on complicated medical issues for their circle of friends, yet this role of helping others comes with its own pain. Feelings of rejection from friends result, as “It’s too hard for some friends that I am ‘experienced’ in loss of a baby.” Cate went from being the “expert” on infant loss to being held at arm’s length when the friend’s baby was doing better than expected after birth – Thomas says, “It’s like we’re the grim reaper – they don’t want us around.”

**Parents of a baby, again**

Liz and John and big sister Caroline love and hold and marvel at their “third” baby, Michelle, who looks amazingly like Teresa. Like the other parents in the group, they have learned to quickly fend off unhelpful comments from well-meaning insiders and outsiders. After Teresa’s death when Liz was pregnant with Michelle, a friend made the comment that she must be looking forward to having her second baby. Liz is adamant to “not erase Teresa’s existence - Teresa will always be our second baby and this baby will be our third.”

Cate and Thomas are overjoyed with their daughter Rose, who is now twelve months old and born nearly a year after Tommy died. Cate says Rose needs her big brother: “Rose has a second child personality . . . she’s a second child by nature, a first child by nurture – it’s a very interesting phenomenon.” Wistful longing strikes at unexpected times: “It happens when I see a two-year-old boy – Tommy would be two.” She continues: “We were at a festival and everyone was out on the dance floor and I saw a two-year-old boy dancing and clutching his mom’s skirt – I lost it on the dance floor.”

Parents use markers to ground themselves as they process the loss of their babies. Cate and Thomas anticipated Rose bypassing the age that Tommy reached when he died – nine weeks. “Since she passed that mark, it’s like we’re in new territory – we’re not experienced as parents of a baby older than nine weeks.” During one group session, Liz and John looked at it another way: “Michelle is now two weeks older than Teresa was when she died – we will always be parents of a baby.”
Alison and Dennis are now 37 weeks pregnant with their second baby and ultrasounds have revealed areas of concern - again, dilated ventricles. In a moment of exasperation, Alison wondered out loud to the group, “What is wrong with me – why can’t I just make a healthy baby”? The other parents’ nod, as they all recognize that life holds no guarantees. And Alison is grateful she can speak without being judged. She and Dennis continue to monitor the status of their yet-to-be-born daughter, and hold hope for a healthy baby. In December, they attended the annual international candle lighting service and, Alison shared with the group afterwards, as they were lighting their candle for Rebecca she felt the baby in her womb move. She finds it hard to explain the experience with words but the meaning, for her and Dennis, is clear – this family, these sisters, will always be connected.

Meeting with other parents in a supportive environment has been integral in the work of healing. Cate sums it up for everyone with the sentiment - “I am so grateful that I can take these two hours every month to just talk about Tommy – my life is so busy now with baby Rose, this is a place I can talk about losing him and missing him and everyone gets it.”

Searching for meaning

Be present with these parents in their truth - I often think about the young couple I visited and the baptism performed in the hospital on that early spring day, and wonder what ways they have found to honor their daughter’s life. The parents in our yearlong group agreed that finding meaning and connection with their children will be a lifelong quest. Yet, for them the energy and passion fueled by their losses has already inspired research into early prenatal genetic testing, volunteering with sick children, or supporting others who are vulnerable and scared. Beyond this particular group, other parents have started foundations, run marathons, climbed mountains, and in other creative and personal ways brought attention to a cause that might lead to a cure, or to ending infant and childhood death. Through all of the tears, despair, and suffering from their losses, parents continue to speak their children’s names, keep their memories alive, and hold hope.
The year was 1976. In Branford, Connecticut, the first American hospice had been serving patients and families for two years. Seven years after the publication of her groundbreaking book, *On Death and Dying* (1969), Elisabeth Kübler-Ross was teaching us how to talk more openly about the subject. Still, many U.S. hospitals continued the practice of whisking stillborn babies out of the delivery room without allowing mothers the opportunity to see or hold them. The belief was that it was in the “best interest of the mother” to spare her the tangible evidence of the death. In addition, the grief following stillbirths, miscarriages, and neonatal deaths was discounted due to lack of understanding of the bonds of love and hope that had already been formed by expectant parents. As our family learned that year, society also discounted the grief of adoptive parents following the loss of an awaited child due to death, injury, or reclamation by its birth mother.

From the time we started dating in college, my husband, Marc, and I talked about our concerns for the planet in regard to overpopulation and its impact on the diminishing resources of Earth. Having read biologist Paul Ehrlich’s book, *The Population Bomb* (1968), we felt it made more sense for us to adopt children who needed parents, rather than produce more American “consumers.” In 1970, we joined a grass-roots movement called Zero Population Growth (ZPG) which strongly advocated for responsible birth control and adoption. When faced with the happy “surprise” of our daughter’s conception later that year, we took the step of a vasectomy for Marc prior to my due date, to remain true to our commitment to adoption. The birth of our daughter in 1971 allowed us to experience the “other” way of becoming parents and made us even more excited about adding to our family through adoption, knowing Tara would have the fun of being a “big sister.”

Our first attempt to adopt was in 1972 in Kentucky. However, we were told that we would essentially remain at the bottom of the waiting list because we had chosen voluntary sterilization and therefore were not as “deserving” of a child as an infertile couple. Thankfully, the adoption environment in Minnesota (where we moved in 1974) was more open. After nearly a year of interviews, home studies, and classes, we were approved in December of 1975 to adopt a child from Korea. As graduate students on a very limited budget, we were eligible for the agency’s sliding-fee scale.

For months we had been gazing at the photo of “Kim,” a precious baby boy with almond eyes and downy black hair, much as expectant parents now put their baby’s sonogram photos on the refrigerator. His room was ready for his arrival, expected in ten days, and the crib sheets and receiving blankets were freshly laundered. Downstairs in the small dining area of our student-housing apartment, a shiny new
highchair was in place – a special gift from other graduate students in my husband’s department who had
pooled their money to give him a surprise baby shower.

Then the phone call came from our local adoption agency: “We’re sorry to inform you that the child you’ve
been waiting for has been critically injured in a fire and will not be arriving next week as planned. We’ll
need you to come to our office tomorrow morning and bring his paperwork with you.” Marc, at home with
the flu that day, called my workplace sobbing and almost incoherent as he relayed the information to me
and begged me to come home right away.

While he waited for me to arrive, my husband had called our pastor, seeking comfort and prayer. Upon
hearing that Kim would not be arriving as planned, the pastor’s first words were, “That’s funny; do you
think this is a scam and they plan to keep your money?” Marc was stunned by the insensitivity of the
pastor’s comment. His emotions were that of a grieving father, but the pastor saw it more as a financial
transaction gone wrong and did not understand the emotional pain Marc was experiencing. Perhaps his
counsel was focused on financial concerns simply because he could not comprehend the devastating
emotional impact of this loss on us.

Likewise, when we met with the agency director and our caseworker the next day, the issue of our grief
was not addressed. After a brief apology for the “unfortunate incident,” they provided gruesome details of
the drastic extent of his burns – and his poor likelihood of survival – as grounds for removing us as his
prospective parents. As graduate students, we did not have sufficient resources to afford the years of
surgery and physical therapy he faced if he survived, and we had no legal right to contest their decision. It
was then that they took possession of Kim’s paperwork and photo. (They were unaware that the previous
night I had gone to the public library to make Xerox copies of the only photograph we had of him. There
was no way I was willing to take a chance of losing my only image of our precious child.)

I was shocked and confused by the way our feelings seemed to be ignored; there was no offer of
counseling at the adoption agency nor was a referral made to a community counseling resource. Instead,
the focus of the conversation was the fact that the agency was going to expedite the process of finding
another baby boy for us. Was that supposed to cheer us up, or help us forget about Kim? It felt almost as
if we were in a pet shop and was expected to simply trade in a sick kitten for a healthy one. I could not
understand how well-intentioned people, who clearly valued the life of each orphaned child, could be blind
to the grief caused by the loss of such a child. We never held Kim in our arms, but we had cradled him in
our hearts and souls during the months of waiting for his arrival. For many weeks, my arms literally ached
to hold him. I felt a compulsion to journal by writing daily entries addressed to Kim, expressing the deep
grief I felt and asking hard questions about where God stood in this whole mess. Our parents tried to be
supportive, but much of the encouragement they offered emphasized the need to “move on” by preparing
to meet our new son, Joshua. Perhaps they only thought of Kim as a photograph and not a living child
who had met with a terrible fate. Inwardly I felt like a bereaved mother, but wondered if I even had a right
to feel that way. Validation of my grief seemed nowhere to be found, and Marc’s need was to close this
painful chapter in our life and not look back, preferring to be caught up in the anticipation of waiting for
Josh.

On the eve of Josh’s arrival three months later, I wrote a long letter to Kim in my journal. I felt I had to tell
him that he would always occupy a space in my heart and life, and that the mother-child relationship I
would build with Josh would be its own unique and special entity, in no way a replacement for the one I would have had with Kim.

From the moment Josh was placed in my arms on June 14, 1976, he was absolutely ours. That exciting day was also a little bittersweet, as I thought about how we had also loved and prayed for Kim, who never experienced our arms around him. As the years passed, I would occasionally bring out my photo of Kim from the dresser drawer and spend some quiet moments remembering him. In no way did it reflect on the tremendous joy I found in watching our beautiful son grow, but the loss needed to be recognized for its significance in my life.

Two decades later, the validation I had sought came in an unexpected way. In January of 1999 I was browsing through Adoptive Families Magazine in the public library, and my attention was caught by an article entitled “Mourning for a Child We Never Met,” written by Carrie Howard. It described her experience as an adoptive mother whose baby girl died in the orphanage in China on the day before she and her husband were scheduled to take a flight to pick her up. The author’s words could have been my own, as she described the grief and confused feelings caused by what is now termed a “failed adoption referral.” In contrast to our experience in 1976, Carrie’s adoption agency was in frequent contact with her in the weeks following the baby’s death, allowing her to feel her grief was validated and acknowledged as “normal” even as she and her husband anticipated the arrival of their “new” daughter. It was good for me to read about how the formerly discounted grief of adoptive parents has been given more attention and credibility than was the case 35 years ago. The fact that such parents can now find validation and support at such a painful time is encouraging to me, as a bereavement counselor and as a mother who experienced the loss of an awaited child.
A few years ago I was invited to attend a seminar. At one point, almost as an aside, the speaker abruptly
stopped her presentation and peered intently at the group that seemed anxious for words of masterful

“For sale
baby shoes—
never worn.”

A shock and hush fell over the crowded room, as everyone pondered the words that were so fresh in their
minds. The quiet stretched for what seemed like minutes, but was far, far shorter. “You know,” the
speaker said softly, “the same silence fell upon the room when I first heard that, too.”

I thought about her words and the ensuing silence and finally surmised I was sitting in a room surrounded
by people whose lives were not touched by death—no, I can’t say “not touched by death,” because we
have all been touched by death. But rather I decided they had not been impacted by a death that had
come up and struck them in the face with the wallop of a 2 x 4. In my work with The Compassionate
Friends, a day doesn’t go by where I don’t talk with someone who hasn’t been slapped in the face with
the reality that their child has died and the future no longer holds the same meaning for them.

Yes, sadly, in The Compassionate Friends organization we deal with “short novels” everyday. Sometimes
the novel and the shoes left behind are respectively a little longer and a little bigger; perhaps toddler’s
training shoes, or ballet slippers, or hockey skates, or maybe they made it all the way to golf shoes before
the novel abruptly ended. But each represents a book that ended much too soon, and each represents a
family left to grieve.

My son was five and my daughter was eight when the accident claimed their lives on the first day of
spring many years ago. Those shoes were so small, the novel much too short.

In the early days of grief those of us struck by tragedy wonder how we will survive—and then we’re
almost afraid we will, because surviving, we are sure, means that we will have to feel this horrendous
ache for the rest of our years.

Sometimes when I think about new grief, the image of Jacqueline Kennedy standing next to her
husband’s coffin, clothed in a black veil, enters my mind. I was young when President Kennedy was shot,
but the image of Jackie, hidden behind that veil, has lasted a lifetime. Maybe that’s the reason why I associate it with new grief. When we are newly bereaved it is as though we are clothed in a black veil—everything we do, everything we see, is filtered through the image of grief, our black veil. And it is so very, very thick and so very, very heavy.

We see a sporting event on the television and we wonder, how can they be playing? How can life be going on as normal? Don’t they know my child is dead? We go to the grocery store and “lose it” when we spot our child’s favorite food. We hear someone complaining about how they’re always having to pick up their child’s dirty socks and we think how lucky they are to have such a “problem.”

Our friends and family aren’t sure what to do for us. Should they laugh with us or cry with us? Should they hold us or run as fast and as far as their legs will carry them? We want them with us—but yet we want to be left alone. We love them—but we’re angry with them. And, nobody in the world understands us! We’re absentminded, easily distracted, and quick to anger. And our self esteem? It’s shattered because no matter how big those shoes were we, as parents, should have been able to protect our child from dying before us.

The black veil surrounds us from the time we awaken in the morning until we go to bed at night. We eat with it, sleep with it, shower with it, and yes, we curse it. Through our tears and sadness we dream of our old life—the one in which mundane things were not really so mundane after all. And, we wish with all our might we weren’t wearing “the veil” that stole our innocence.

Sometimes the veil slips off and we receive tiny respites from the weight of carrying the black veil. In these respites we may feel almost embarrassed that the weight of the black veil has been lifted for just a moment and we are now open to a small measure of happiness when pain has been our constant companion. But it wasn’t only pain that was with us—there was shock, and anger, and questions of faith, and questions of the meaning of life, especially a life cut so short, still wearing shoes that will never be outgrown.

Over time the veil fades from black to gray. We still carry it with us but our emotions are easier to control. The fog that has so enveloped our thought processes starts lifting from our mind. And we see that there may actually just be a reason to go on living. For everyone these reasons are going to be just a little different—the realization other members of our family need us, the birth of a child, a cause in which to invest our energies, or we may simply find a new friend who is struggling with the same loss.

Yes, life deals us some terrible blows. But along with those terrible blows we are given the ability to survive—a survival we, for a period of time, thought was impossible. I have heard the analogy that losing a child is like losing a limb from your body. The body may heal, but the stump, even fitted with the best artificial limb, will never let you lift things quite the same, or walk quite the same. You may not run again, at least not as fast. And you may not be able to lift things that are quite as heavy. But you learn to adjust to the new you. You learn what you can handle and what you can’t, and how you will have to approach it within all aspects of your life. You learn how to survive even without that limb.

Yes, we will survive when our child dies. Working through tragedy seems today almost like a part of life. The question becomes one of how we handle it—what our child, sibling, grandchild, or close relative would want for us. In the end we must reach the realization that it’s our job to give it everything we’ve got.
to fill the shoes that were left behind—for even the shoes of that shortest novel ever written will be so very, very big to fill.

Patricia Loder has been executive director of The Compassionate Friends since 2000 and helping those living with “too short novels” in their family for 18 years, when she and her husband chartered a chapter of The Compassionate Friends. The Compassionate Friends is the world’s largest self-help bereavement organization and through its more than 625 U.S. chapters provides outreach to nearly 200,000 bereaved families and professionals every month. TCF/USA has locations in every state, a very active Facebook Page with well over 20,000 members, and an Online Support Community which can be reached through its national website. Annually it sponsors The Compassionate Friends Worldwide Candle Lighting the second Sunday in December in remembrance of all children who have died, an annual national conference, and Walk to Remember. Call 877-969-0010 or visit www.compassionatefriends.org for more information on the organization.
When I was asked to present some case examples of complicated bereavement, I thought there is really nothing more complicated than the death of a child. I have been a Mental Health Counselor for a children’s palliative/hospice care program for 11 years and have been involved in many deaths. As we know, the grieving process does not begin at the time of death but at the time of diagnosis. My goal has always been to help support, prepare, and facilitate what we refer to as a “good death.” For the most part, that goal can be achieved as complicated as it is in experiencing the death of a child. If the families perceive that their child’s death was “good” and we did our job to support them through anticipatory grieving, then the bereavement process can be less complicated.

Complicated bereavement involves additional barriers that slow or prohibit the normal grieving process. Some examples of what complicate the grieving process can be: a traumatic death, history of previous losses, a strained or difficult relationship with the deceased; and of course the death of a child. Another example would be multiple deaths in the same family. I have worked with several families over the years that were not only facing the death of their child, but had also experienced the loss of the child’s parent or sibling. This presents a unique challenge for the support team working with the patient and family. It is important to recognize the multiple layers of grieving, the need for closure from the previous death as it impacts the current one, and the power of forgiveness.

I reflected on this challenge as I was leaving Mathew’s death early on a Sunday morning four months after his admission to our program. Mathew was 17 and had battled Leukemia for two years. He had a dry wit, love of life, and amazing sense of peace. He told me his sense of peace came from his faith in God and knowing he would see his beloved father in heaven. His father, Mike, had died one year previous from heart disease leaving behind his wife and six children. Mathew was receiving a bone marrow transplant at the time and his mother had to make the painful decision to have his father placed at an inpatient hospice facility so she could be with Mathew during his transplant. His father resisted the inpatient admission, not wanting to be away from his family and ill son. There was really never a good-bye, just a phone call to Mathew’s hospital room informing his mother, Sharon, that his father died in the middle of the night. Sharon made it very clear to me on our first visit that Mathew will not die at home. She was not going to put herself and five other children through another agonizing death again. However, Mathew made it very clear to me on our first visit that he wanted to die at home with his family and where the memories of his father are. It was evident that there were more barriers than a roadside construction site to complicate this grieving process and impact any sense of closure.

What was so apparent during my time in working with Sharon was her anger; anger at her husband dying, anger that her oldest child was dying, and anger at hospice since that is where her husband died. I
equate my visits with Sharon to walking on thin ice. I was never quite sure where to step since there were so many cracks. Many of our talks focused on her husband’s death and allowing the expression of anger. She also shared being angry at Mathew for some incidental things he had done in the past. It was easier to be mad at him for some teenage misbehavior then for dying. The concept of forgiveness was essential for Sharon in her healing. I encouraged the process of forgiveness one day after she vented her feelings of frustrations. She certainly had every right to vent and to question what fairness there was in her life. Unfortunately her anger kept her stuck. Mathew was going to die and she could not bring herself to have any time for good-bye. I feared it would be another lost good-bye for Sharon and for Mathew. Her pastor was a strong presence during this time. In many ways he assumed the role of father to Mathew and his siblings. He and I would spend many hours reviewing what this family needed and he was instrumental in assisting Sharon with the process of forgiveness. You see the main person Sharon needed to forgive was herself. She was most angry at herself for “the wrong choice” she perceived in placing her husband in a hospice facility. With the support of her church, our team, and her family, Sharon was able to forgive herself. I remember seeing this unfold. From that point on, every moment counted. At Mathew’s death, Sharon was eager to show me and our nurse pictures of positive memories: Mathew and her sky diving, race car driving, the air balloon adventure, and countless parties at home with friends and family. There were pictures of Mathew and his siblings all in their mother’s bed watching a good movie. My favorite one was of Sharon and Mathew wrapped in his favorite orange and blue Florida Gator blanket together. Her hand was gently rubbing his head and it looked like she was whispering something to him. I wanted to know what she was saying to him since he looked so peaceful in the picture. I realized this was a private moment shared between a mother and son so I did not ask. It was a time for good-bye that she did not have with her husband. Sharon hugged me before I left that morning. “I am glad he died here,” she said with a grateful smile and watering eyes. Mathew died at home peacefully in the loving arms of his mother who was able to forgive her husband, her son, and herself.

I remember meeting Kristi and Rick for the first time in the children’s oncology clinic. I recall their pained faces as they were told there is no other form of treatment for their six-month-old son, Sean. It was a rare tumor with no options for a cure and with no rhyme or reason why a six-month-old child should have to endure this in the first place. What was most striking to me was Sean. He sat calmly in his mother’s arms enthralled with her watch that he could not pull off her wrist no matter how hard he tried. Sean had piercing blue eyes, a million dollar smile, and a perfectly round bald head. I remember him touching his perfect round head at one point catching his mother’s tears that had rolled down to his nose. I spent a good bit of time with Kristi, Rick, and Sean after the oncologist had left. I commented on Sean’s calm demeanor and cuteness. I asked Kristi and Rick to tell me about Sean. They greatly obliged and smiled as they told me about their six-month-old son and for a moment relaxed. We discussed what was most important to them now. Kristi did not hesitate. “I have to be with him when he dies. Please promise me that will happen.” She said this with such urgency that I did not want to tell her that sometimes this is not always the case. “No suffering,” added his father. They wanted him to be as comfortable and happy as possible. I can honestly say that Sean and his parents were one of those families where there was an instant connection. By the end of our time in clinic, Sean had me and his parents giggling and laughing with his funny expressions. He almost seemed to sense the mood and the need to lighten it up a little.

With rapport being established fairly quickly, Rick and Kristi were very open in expressing their feelings and working on quality of life goals. Kristi reinforced her goal to be with Sean at his time of death and why this was so important. Two years ago their three-month-old daughter, Ashley, died of SIDS while at the
sitters. I had some information on their other child from the oncology clinic, but felt it was important for the parents to tell me first hand. It was early evening when we had this discussion and Rick had just come home from work. Sean was somewhat fussy that day and Rick ended up bouncing him in his arms while Kristi shared what happen with Ashley. Ashley was a healthy baby who went to the sitters during the day while her parents worked. Her mother had noted a slight running nose that morning but otherwise seemed very content when dropped at the sitter’s home. Once at work, Kristi thought it was best to check out the running nose and made an appointment with the pediatrician for the following day. At lunch she received the call that no parent wants. Ashley had been taken to the ER. She had stopped breathing. Kristi notified Rick and they both raced from their jobs to the ER. They found Ashley hooked up to tubes and machines. The attending physician told them he was sorry. She had arrived to them not breathing and already dead. “I was not with her when she died,” Kristi said again with a numb face. Rick shook his head agreeing. “I was not there either.”

In the months that followed the death, they attended a SIDS support group at their church. Both parents researched the causes of SIDS so much so that they actually provided education to several of the support groups. There was an extensive investigation of the sitter which did not produce any clear answers except that Ashley most likely died of SIDS. The intense need to be with Sean at the time of death was obviously clear. Even clearer was the need for Kristi and Rick to forgive themselves for not being there for Ashley’s death. This had to take place in order for them to begin grieving Sean’s illness and his pending death. It was important for Rick and Kristi to retell the story of Ashley’s death and forgive themselves for what they could not control. Many parents work and take their children to sitters. Many children have runny noses and do not die. It was important for them to build positive memories with Sean and hold him at all times. It was important for them to have mommy and daddy time and allow our wonderful nurses to care for Sean so they could have a date night. It was important for them to hope for a healthy child one day and to have some sense of closure that they did not have with Ashley. It was important for them to realize they are caring parents to both their children. Both Rick and Kristi worked hard in allowing themselves to grieve and allowing forgiveness. Again, they needed the support from their church, family, and our team for this process of healing to occur.

It was a Saturday around 6 am that I sat with Rick and Kristi along with one of our hospice nurses. They were holding Sean much in the same way as when I first met them in clinic. His mother was gently caressing his perfectly round bald head while his father cradled his tiny body. “This was a good death,” Kristi said. “We did everything for Sean that we could not do for Ashley but would have done if we had that time,” she added. “Sean and Ashley had the best parents. They knew nothing but love,” I said. “We believe that,” Rick said. That is really all I needed to hear to know that they had forgiven themselves and were now able to grieve with less complications.

With most cases where there is complicated bereavement, the theme of forgiveness is a key component to healing. No family should have to experience the death of a child let alone another child or parent. However, in both these cases the second death actually provided the sense of closure the families needed to be able to grieve the first one. It is important as members of the care team (nurses, physicians, social workers, chaplains, and counselors) that we recognize this need and help facilitate this process. We should never underestimate the power of being present for these families. They need a sounding board, guide, validation of their care, and acknowledgement that they need to forgive. This will allow them to focus on the here and now with their dying child, rather than hold onto the past regrets. I have a motto...
that I tell all patients and families when we first meet, “NO REGRETS.” It is up to the family and patient to
define what these regrets are or could be and it is our job to assist them with resolution. Also, be sure to
utilize their existing supports; family, friends, and faith community. Help them identify who can provide the
unconditional regard they need at this time and work with those supports as a team. Not only will this
collaboration strengthen the grieving family but will actually give support to the support system. The most
encouraging words I can hear as a counselor is when a patient and family say, “I have no regrets.” This
lets me know that as the care team, we did our job and that the family’s bereavement journey will be less
complicated.
WHEN A PARENT IS DYING

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Most hospice and palliative care programs are accustomed to caring for those at the end of life who had long and fruitful lives, who are elderly and maybe even very elderly. They are dying in the “natural order” of what we expect in our society. When the patient is a younger adult, one who still has children in the home, or who is younger than the norm, we see some additional stressors in the staff and more emotional responses to caring for a dying parent with dependent children. These “non-traditional hospice patients” and families can trigger very powerful and meaningful experiences—for the hospice care team.

The question is: are our efforts to help children coming too late? Do we only think of children when we know they are bereaved, after a death, and then refer them to a local grief camp or support group? Do we think of “children in hospice care” only as pediatric patients? Perhaps our programs are not large enough or resourced enough to take on a whole new level of grief support but there are avenues to do something in simple caring ways, all the way up to a specialized bereavement program focusing on children, teens, and young adults.

Scope of the Problem Before Us

It is estimated that over 2 million children in the U.S. (slightly over 3%) experience the death of a parent before the age of 18. Almost three quarters of these deaths are anticipated (Goodman, n.d.). The numbers are significantly higher when grandparents, siblings, and friends are factored into the number and types of deaths experienced by children under 18. These numbers should cause us to pause and seriously reflect upon how we as end-of-life specialists can do more to alleviate the burden and distress of the long-term impact of death on children. These children and teens are going to school, playing sports, attending church, and participating in clubs. They may be going to their bedrooms at night with questions, fears, and unspoken worries. They are eating meals at dinner tables impacted by the death of their loved one. The reality is that children are already exposed to death and grief but are often not well addressed in the midst of family dynamics, often protected from participating in goodbyes, funerals, or memorial services; and therefore kept from the opportunity to understand, find meaning, hope, and normalcy.

Consider another age group that is really under the radar for most bereavement programs—grieving college students. According to the National Students of AMF (www.nsamf.org), a non-profit organization that helps support development of on-campus grief support groups with and by college students:

- “Between 35% and 48% of college students have lost a family member or close friend within the last two years. Between 22% and 30% of college students have lost a family member or close friend within the last year”
• 18.4 million students were enrolled in American colleges in 2009 (U.S. Census Bureau, 2009). That equates to more than 4.5 million college students who are grieving.
• 8.6% of college students’ academic performances have been affected by the death of a family member or close friend within the last year.
• Research shows that a student’s GPA significantly decreases during the semester of loss, providing empirical support for the assertion that bereaved students are at risk for declined academic performance.
• For 10% to 15% of the bereaved, a debilitating and prolonged form of grief can pose severe long-term risks for psychological and physical health.

According to the National Cancer Institute, one in four cancer patients have a child younger than 18 and an estimated three million children live with a surviving parent after the death of their mother or father (Rauch, 2006). This creates significant impact for the hospice patient population since a majority of hospice patients have cancer diagnoses. It creates the urgency of addressing these adult patients as multigenerational families rather than within a patient/caregiver framework. Prior to the parent reaching end of life there are opportunities for our collaborative efforts with cancer centers and other providers to integrate strategies to help both children and parents before their time together runs out.

In good clinical management of physical pain, we strive to get ahead of the pain by scheduling medication to prevent it from getting out of control and preventing unnecessary suffering with a plan. Apply the same principle to emotional suffering and anticipating the death of a parent for a child, teen, or young adult. Whatever we can possibly do before the death to prepare, support, educate, create legacy activities, and capture hopes and dreams between parent and child, we are investing in the future wellbeing of that young person. With a new awareness of the needs of all children under our care, we must adapt our care to include the children of our adult hospice patients as vital to fulfilling the mission and purpose of hospice and palliative care programs. The investment may not yield results until we are long out of their lives, but the effort, attention, and expertise provided to families and schools in support of their emotional needs will have long-term impact and results on them as individuals, families, schools, and our communities.

How We Can “Institutionalize” Support for Children in Our Adult Programs

When an adult patient is admitted, routine questions can be asked to determine if there are children or young adults impacted by this person’s serious illness and to identify their ages. This can happen at intake level or at admission, information visit, or if appropriate on the initial intake call. The social worker can then focus support strategies for the family as a whole, even when the children may not be present during visits. In the case of students at college, the team can offer suggestions to the parent on how to include the student in the situation, keep communication open and honest, and encourage them to seek support and help on campus, to let their RA know or their advisor. Allow them to come home if possible to be part of the illness experience, even just visits, with the understanding that this adds another burden to grieving students to maintain their grades, scholarships, jobs, and other responsibilities while coping with a parent’s illness and possible death. Often they have a caregiving role as well.

The team can inquire as to what supports exist for the children of any ages. Does their school know about the family situation, their church or faith community, the coaches or teachers? The school nurse? Often
school nurses report that students come to them more for emotional needs than physical, a fight, sadness, and turmoil at home, unspoken stressors. An “alerted” school nurse may be an oasis of comfort to an anxious child, but will be limited in doing so unless the parent notifies those who are in a position to help their child. The hospice team can intervene to be a liaison to the school team to mobilize supports on campus or to at least raise awareness of those close to students so they can be more attentive to troubling behavior or increased stress, emotional reactions and fatigue, missed work, etc. Communication between the hospice/palliative care team and the child’s school can also help to facilitate a network of informal helpers, the model of “Share the Care” that allows many people to help within their comfort zones and not get overwhelmed, all within the scope of their own comfort level of tasks (see www.sharethecare.org). This model allows for many ways to provide help to parents for their children to insure routines are kept, errands done, sports and clubs continued for the child’s sense of normalcy if possible.

The nurse can also add support to the children in adult patient families by helping the child understand in simple terms what is going on, once they have agreed upon this with parents. Hospice staff can also create a safe space to discuss these issues. Information may be helpful to “translate” what they are seeing, hearing, and feeling around them but may not have been given the words or information to make it make sense.

We can also utilize the expertise of the pediatric staff if the organization has that specialty programming or has a more extensive array of services. The pediatric team staff can be an internal resource to facilitate education on normal grief and loss responses by age, as well as how children and teens interpret information at different developmental stages. Pediatric teams can bridge the chasm between care of sick children and better care for children in the families of adult hospice and palliative care patients. This approach is a wise use of resources to access them for both overlapping areas and it also helps justify the expense of specialized staff.

Our support to children and families when a parent is dying needs to be individualized as in all other aspects of care with attention to spiritual and faith traditions, culture, family dynamics, openness of communication, rules set by parents, and ability to interface with the young family members. It does need to be offered, attempted, and revisited over time and provided with sensitivity and gentleness, paced at their openness to the readiness of these interventions and conversations.

**Preserving a Parent’s Presence for the Days Ahead**

Creating keepsakes and legacy items is a powerful way for some families to preserve the connection between parent and child long into the future. When the situation allows (and the patient is not hours from death), the team can suggest and assist in the creation of humble but important concrete reminders of their relationship. Especially for parents with very young children, this may be very important if the child may be too young for their own memories. Questions and mysteries abound in the years ahead when there is little evidence of who that parent was. It can be as simple as the following inexpensive activities. Make handprints of the parent alongside each child (no age limit here). Add other family members and a family portrait of handprints emerges. Create a memory box that children decorate with parent. The box can hold items to remember favorite places, special days, work life identity, favorite foods, perfumes or
cologne, sports and activities shared, family roots and heritage-related items, and/or religious items of
meaning. The idea is to allow for families to use the time they do have to make time to gather items,
photos, and stories while the parent is still alive. Some parents may wish to write letters for special
milestone days/events in the future or a letter to validate their feelings, their hopes, and dreams for the
children. Some videotape these messages or record voices, story reading, and singing favorite songs,
narrating a remembrance of special times. These may be very emotional for the parents as well and
understandably will not be for every situation but are worth exploring with families and assisting them
with staff or volunteer projects. Creating an Ethical Will from parent to family is a beautiful way to preserve
one’s life wisdom, core values and driving passions, lessons learned from life’s challenges, inspirations,
and how they got through tough times. (See www.ethicalwill.com for ideas and resources).

Parenting at this challenging time near the end of life is worthy of our utmost compassion and attention,
knowing that the time the children will have without their parent pales in comparison to what we spend
with them. We are able to arm parents with ways to find peace and some relief knowing their children are
better prepared or at least will have a safety net of care when the parent will no longer able to provide it
themselves. They may find peace in letting go if they feel confident the other parent or family members
have a plan to preserve their presence in the life ahead for their children. It occurs too often that a parent
enters hospice care and is very near death, having extended any means possible to have more time with
family and yet has not tended to the communication with their children about what comes next when they
are gone. For some, the plan for who will be guardian and provide care for the children is not even
prepared for at this late stage of end of life. How healing it might be if, for those who can, they can tell
their children, teen, or young adult that their love for them does not end when they die but lives on
through them, through their shared memories, special places, rituals and favorite meals, foods and
traditions. They will also benefit from being able to choose, when the circumstances allow, to take part in
a memorial gathering—once they have been prepared for what to expect—with all their senses and have
a guardian (trusted friend or relative) to attend them who can escort them out if needed or take a break
from the gathering if desired.

There are many factors that influence how children adapt to a parent’s death. Some factors include: type
of death and the physical functioning of the surviving adult/parent, as well as the emotional response by
that adult. Other important factors include demographic characteristics such as age, demographics,
socioeconomic status; the child’s temperament and personality; pre-existing factors such as mental
illness, learning and social problems; family structure, functioning, and relationships; quality of the parent
relationship before death; other life stressors at same time such as financial strain, living situation,
divorce; support services available before and after the death (Goodman, n.d.).

The missing piece in families when a parent dies is pronounced and enduring. Children may feel alone in
their grief if they don’t think anyone else has ever been through this before at their age. The founder of
Comfort Zone Camps, states, “Childhood grief is one of society’s most chronically painful yet most
underestimated phenomena.” Children participated in an extensive New York Life Foundation study,
“Exploring Grief’s Landscape: A National Research Perspective” that focused on both children who had a
parent die and adults who were bereaved as children (www.hellogrief.org). The study highlighted the
impact that early loss of a parent causes in the lives of children. Many children reported that they
frequently pretend to be OK to avoid upsetting the other parent whom they know to be very sad. Many
children also reported fearing the other parent will get sick and die. Nevertheless, it is also true that the
early loss of a parent can make children more resilient and they can grow over time in many ways as a result.

The enormity of the loss of a parent may not emerge until children are older, the full scope becoming realized over time. As young adults they reach milestones that mark the absence in a fresh new way, triggering memories and the opportunity to make sense of the loss. Learning to drive, picking out a prom dress, first dates, graduations, and planning for college or a wedding are all examples of milestones to be faced and adapted to when a parent has died. The lifelong challenge to adapt can be mitigated with caring adults who exist in schools, faith communities, and other communities offering grief support, recognizing the roles they can play in the lives of grieving children, teens, and young adults. The loss and absence endures through their lifetime.

Schuurman (2003) uses a retrospective approach to provide many insights into the journey from grieving child into adulthood when a parent dies. She illuminates why bereaved children who become adults are “Never the Same.”

Many schools are open to grief support groups offered by hospice programs or other grief specialists in a community. Make those connections to enhance the collaboration between the community and our clinical programs. Seek occasions to share resources, grant opportunities, and other efforts to reach out to faculty, parents, and students. This collaboration also strengthens the foundation for subsequent hospice referrals from adults who have a seriously ill parent, spouse, or other individual. By exploring any ways that we can strengthen conversations around grief, end of life, and finding healing and hope, we are creating healthier communities as a result.

Transitioning to bereavement follow-up may be another place to insure continuity, to create a seamless handoff to whoever follows the bereaved. This is where “family-centered care” takes on a new meaning in that our bereavement care must also reflect care not only for the caregiver noted on the documentation. Hospice teams are encouraged to really commit to increased awareness of children impacted by the death of any patient and insure appropriate follow-up support is made available to them through hospice bereavement or other community grief support programs. The aim is to insure that the children and family do not experience a precipitous change or loss but have an overlap or at least are prepared by the primary team as to what to expect, who will be in touch, who they can access for help and support, and what to expect in the early grieving experience. It is critical to know what local resources for children are available. This is one area in which we find little competition among hospice programs since the needs are so great and resources scarce. We are wise to explore what is already in place and working, and to seek to create solutions for those needs that still appear to be unmet. Identify who is providing bereavement camps, groups, classes, school groups in your region and support those; create those that don’t exist at all if you see the need, opportunity, and will to do it!
References


www.ethicalwill.com
www.sharethecare.org
www.nsamf.org
www.comfortzonecamp.org
www.hellogrief.org/about/life-with-grief-research/
This article is about what grieving children need from adults, i.e., parents, teachers, counselors and health care providers, when someone they love is dying. It contains a discussion about the not-so-helpful, but familiar patterns that adults often revert to when facing death and grief, and offers alternative ideas that work with children. It also includes a section for elementary school counselors and teachers who encounter loss and grief in the classroom, offering them supportive resources. Finally, it is assumed that pediatric palliative care professionals may benefit from increased awareness about common communication patterns that grieving children may be experiencing within other areas of their lives. Case stories are offered with suggestions for how adults can approach this topic and learn to communicate in a comforting way that helps our children feel valued and loved.

Indeed, it is easier said than done to tell an innocent, carefree child that a family member is sick and dying. An example of a gentle approach might be: “Your sister is very, very sick,” or “Your grandpa was so sick that his body just stopped working.” Children learn as they grow, with increasing awareness and understanding of what death means. They do so chronologically in age and developmentally with tasks and stages. By the time they are teens, they begin to move toward a more abstract thought process about dying, death, and grief. Many opportunities exist to educate our children and families on this difficult topic. Adults can facilitate powerful exchanges that assist children in communicating about death, and after death as healing begins. Coping skills are learned that last a lifetime, and normalize the subject of death and grief.

Jessica’s Story:

My sister has leukemia. That’s what my dad told me. She got it last summer, I think. I really don’t know. I am 9 years old. I have one younger brother who is 6. My sister who is sick is 17. She was in high school and had lots of fun with her friends before she got really, really sick. She got sick because of all the medicine. That’s what my mom told me. My mom seems really sad. My dad just doesn’t say much. My little brother doesn’t know what’s going on. My sister doesn’t have any hair. She looks funny. Right now she is in her bedroom resting. It is dark in there, and kind of scary. I wrote her a note and drew a picture that I want to give to her. My parents will only let me see her if they are with me, and only for a few minutes. I really miss seeing her, so I go in to visit her whenever I get the chance. She smiles and holds my hand. I wish that she never got this leukemia. I miss her so much, and our family the way it used to be.

Reassure Me, Don’t Shut Me Out:
Jessica’s story highlights the thoughts, feelings, questions, hopes, wishes, confusion, and fears that all children have when someone they love is dying. More than ever, children need reassurance that their family will not fall apart and that they will get through this sorrowful time together. Children pick up on nonverbal cues which often are more powerful than words. Very often, a disconnect develops between parent and child, so no one is talking about the inevitability of an impending death in the family. Parents may assume that children do not know what is happening and it is best not to bring “it” up. Children may assume that bringing “it” up will make a parent sad, and sometimes even assume that they are the cause of the sadness. This is the classic “elephant in the room” dynamic that only magnifies a child’s fears and uncertainty. Avoiding discussion becomes the norm, when what children really need is constant reassurance that they will be loved and cared for no matter what. It is often the case that the family shuts down communication at the very time they should be sharing their deepest feelings and supporting one another during an extremely sad life event.

The Loss is the Cause of the Sadness:

Talking about illness and death is indeed one of the most distressing tasks a parent will face. It is especially difficult when they have not learned skills for doing so. And it is a skill. A child may ask a question only to witness that Mom starts crying. An erroneous but common response for this child is, “I made Mom cry by talking about my sister’s death” or “It is my fault. I made Mom sad.” A comforting response for a child in this situation might be:

Oh honey, you didn’t make me cry. Your sister’s death is causing my sadness. It has been very hard for all of us. I know you are sad. I am sad, too. But we will get through this together, and we will feel better someday. It won’t always hurt this much.

Parents, with all the best intentions, believe that by shielding children from the idea of death, they are protecting them from a harsh reality, or they may believe “the child is too young to handle this.” Often it is not the child who cannot handle reality as much as it is the parent. Adult fears get in the way of raising children who can view death as a normal, natural part of life. Children just want to know what is going on. They teach us how to help them – if we listen and provide an avenue for open sharing.

Include me:

It is vital that children be included in the family’s process around the illness and death. If they are excluded, they will make up stories that are often worse than reality, and... perhaps even feel that somehow all of this is their fault. Since no one will let me visit my sister, or talk about what is happening, then it must be me... I must be a bad person. When children are allowed, even encouraged to fully feel their emotions and have their questions answered honestly, they will feel valued and included in the family happenings around an illness and impending death in the family. Doctors and other medical staff are often the first to break the prognosis of a child’s condition to parents/family. If this is done tenderly, then the parents receive the understanding and support they need to introduce the discussion with the sick child and his/her siblings and other family members. We need to honor the thoughts, fears, and anxiety that children have by listening to them and including them in what is going on around them.
Role-modeling is a Powerful Teacher:

Role-modeling is the most powerful way to condition children far beyond instruction with words. Children are conditioned to fear death in the same way they learn to fear bees, spiders, or a dark room. It is in the interactions around the everyday normal “stuff” where parents pass along the implicit rules that they learned as children in their own families. If they are role-modeling silence, the message becomes: It is not okay to talk about death. Instead of using this time together as an opportunity for learning coping skills, adults reinforce the societal, cultural, and generational patterns that deny feelings and discussion about the reality that we all will die someday. And so it goes…the cycle begins again with each new generation—unless we make a concerted effort to socialize our children differently. Just imagine a world where families have adequate skills and opportunities to calm fears, normalize death, and communicate about it all openly. This change of dynamic happens best when the interface of home meets with the various systems that support a child’s socialization. Open systems role model tender, loving communication and support for whatever a child may need.

Teachers and School Counselors: Grief in the Classroom:

Teachers often have a unique vantage point for close, daily observation of their students. They are in a position to serve as a facilitator of children’s grief. If parents have communicated with the school that the family is dealing with a terminal illness and impending or actual death, many opportunities exist within the school to assist the child. Teachers can initiate dialog in the classroom, providing a safe forum for children to understand death and learn about how to comfort each other in grief. Age-and-stage appropriate activities and lessons can be initiated and safe expression of feelings can occur through the use of art, story, or music.

My Story:

As a new bereavement coordinator, I had a lot to learn. Apparently so did the teachers and the principal of a school that had called me to assist them in dealing with a recent tragedy. Our hospice had designed a puppet show with a script that we used to initiate discussion and learn about grief and how to help each other. In this case, a terrible auto accident had occurred where a boy and a girl had witnessed their parents’ death when the van they were driving was hit head on. The children although badly injured, survived the crash. After weeks of healing physical wounds, the girl returned to fourth grade. She had been acting out the details of the accident scene on the playground. Hence, came the school’s request for assistance.

Our presentation included a pre- and post-test, with detailed instructions for teachers before and after the puppet show. I visited the school teacher of that room earlier in the week, and she assured me she would prepare the students as instructed. She did not. Her own fears got in the way and she did not have a comfort level not only to talk with the children, but she could not muster the courage to call me and tell me she felt this way.

The day of the show, my volunteers were at the front of the class delivering the message with our puppets and script. Children were engaged and curious. I was in the back, observing the girl whose parents had been killed. She began to take her sweater up around her head and try to pull her arms out
of the sleeves and curl up inside. She had not been prepared for the topic, and this discussion triggered the trauma. She was seeking safety in the way she knew how to at that moment -- “inside her sweater.” Sadly, we had to pull her from the room.

The teacher was in tears at our debriefing meeting after school. It became clear to me that day that teachers are not always given the resources to know how to deal with death and grief in their classrooms. It is rare if the school counselor has had training and experience with grief theory and counseling, so connection for a child with the school counselor leads to an outside referral. Many families cannot afford private counseling, and/or do not know about hospice bereavement support services (which are free to the community), so help can feel far away and inaccessible. It seems so simple really, to read a story book about death or engage in some art-related play activity that will prompt an open discussion about our feelings and responses. However, it is often the case that comfort level is lacking among those in leadership positions at school. And we continue to condition our children with ideas that make death scary and keep it a mystery.

The striking fact about my story is that it occurred in 1988. Twenty years following, in 2008, my daughter’s fourth-grade class still had no established protocol for handling loss in the classroom. One of her female friend’s had recently experienced the death of her grandfather and was sad and withdrawn in school. Ultimately, the school counselor had a few meetings with her, but she never shared with the counselor that her grandfather had just died! Why would she? No one else in her family or immediate environment gave her permission to do so.

I am pleased to report, that there is a plethora of information now, 23 years following my experiences with school systems. But what continues to surprise me is that the way loss is handled in the schools has not changed all that much (there are some exceptions). Dying, death, and grief are still taboo topics. Although we have seen some movement, it has not been enough to create a comfort level with it. Teachers and school counselors are not accessing the available resources. Even with the Internet, which provides instantaneous connection to electronic information about the topic of death and grief, we are not witnessing established protocol in our school systems and classrooms. A crisis team is often available, but may consist of short term counseling or debriefing techniques that are not designed to deal with terminal illness and death.

Perhaps our school systems across the country could benefit from in-services for teachers on the topic of loss, offering further professional development opportunities. College-level teacher education curricula could offer/require death and dying courses for student teachers about end-of-life care and grief support for children and families. We now have the benefit of palliative care entry into the medical model, so health care providers have more access to EOL care resources and community grief support. Perhaps it is time to implement the same within the field of teacher education.

All They Need is a Safe Forum and Validation:

It isn’t that simple, but it is a beginning. Validating loss means supporting the children wherever they are in their process, so they will feel valued and cared about at an especially vulnerable time. Give a child safety and a place to share with age-appropriate lessons and activities, and watch what emerges. It is amazing, even stunning what children will teach us about how to help them. We need to be present, actively listen, and provide safety and validation for our children.
In Closing:

Indeed, children can learn about death as a normal, natural part of life, and that grieving is a normal, natural process that follows. Families need to communicate openly about an illness and death, and realize that doing so is a learned skill. Health care workers who minister to vulnerable children and their families set the example by approaching the “delivery of the bad news” in such a way that encourages families to dialog openly and honestly. Role-modeling open discussion is perhaps one of the most powerful ways to do this. Health care providers, palliative care professionals, parents, and school personnel need to team up and communicate about what is going on in a child’s life. Socialization about how we grieve will change at a societal and familial level, making it more acceptable and less fearful. We can change the way we grieve, one child at a time.

Note: I have attempted to share my own personal and professional experiences about dying, death, and grief, and what I have observed and found valuable over 20 years of working in this field. Rather than create a list of do’s and don’ts within this article, I have provided resource links and references for readers to access more in-depth information about this topic as needed. I hope this approach is useful.

References:


Further information about grieving children and adolescents:

Suggested Websites:

- **www.nhpco.org** (focus of this newsletter: pediatric care in end of life)
- **www.hospicenet.org** (information for adults about children and death)
- **www.griefnet.org** (chat rooms and other resources for children)
- **www.adec.org** (professional organization for resources and education)
- **www.marcoroducts.com** (Marco Products is a publisher and supplier of lesson books, activity books, games, DVDs, and other resources for guidance counselors, educators, and other professionals who work with children.)

**www.compassionbooks.com**
The Compassion Books catalog is available online. This is an outstanding resource for teachers who are seeking classroom guidelines for children’s grief support. It is also very helpful for counselors, parents, friends, and family. Their catalog is presented in sections, by topic, containing one of the most comprehensive collection of resources available for grieving children and their families, and all those who want to help them.

**www.apa.org/pubs/magination**
American Psychological Association: *Magination Press*. Publisher for storybooks and self-help books about children and grief. Also excellent scholarly resource for professionals in the field who work with grieving children and families.

**http://www.springerpub.com/products(subjects/Psychology/Psychology-of-Death-and-Bereavement** (Springer Publications is an excellent scholarly resource for books on the topic of grief support)

Madonna University, Hospice & Palliative Studies, *End of Life Resources* (link):

When the Resolve Through Sharing (RTS) program began in 1981, planning committee members understood that follow-up care was a necessary component of caring for families after perinatal loss. The purpose of this article is two-fold: to briefly summarize the history of Resolve Through Sharing and describe the "how tos" of follow-up care.

Gundersen Lutheran Medical Center was a pioneer in system-wide bereavement care with the introduction of RTS. The program developed from an interdisciplinary team’s intense interest in creating a way of caring for parents when a baby died that was sensitive, compassionate, and inclusive of the post-hospitalization time. Two maternal nurse practitioners, Katherine Hill Goettl and Carolyn Smiley, provided the practice model for RTS that was based on their experience working intensely with families after stillbirth and newborn death. The one-to-one helping relationship was an innovative approach to perinatal bereavement care which, at the time, was largely offered at most hospitals by teams and through support groups. Once the planning committee had finished their work, Rana Limbo was hired as the first coordinator of the program. During two national speaking engagements in 1983, Limbo and her manager, Sara Wheeler, were surprised to learn of the interest nationally in replicating the Resolve Through Sharing model. Leaders at Gundersen Lutheran asked that they, Goettl, and Smiley write a training manual for perinatal bereavement care, which was used for the first time in Tampa, Florida, in the fall of 1983. Limbo and Wheeler continued to develop and hone the coordinator role and wrote a second training manual. The first national RTS Coordinator Training was held in La Crosse in August of 1985.

These features of the Resolve Through Sharing program were unique at the time and, in retrospect, were responsible for diffusion of the program throughout both Lutheran Hospital and Gundersen Clinic:

- The coordinator role was centralized, but care of the families was de-centralized to each unit where losses occurred. Nursing or social worker staff on a particular unit provided care at the time and did follow-up, thus providing a relatively seamless process.
- Education occurred at all levels and with all staff. Establishing the leaf and teardrop door card as the universal sign of bereavement sensitized all who entered a room.
- The one-to-one relationship with bereaved families resulted in high patient satisfaction, as evidenced through yearly surveys. Survey results were shared with physicians, some of whom were initially skeptical that the program was needed. Reading the comments and seeing the overwhelmingly positive response from parents helped convert doubters.
- Follow-up care was standard. This approach provided additional knowledge about the families’ experiences and was reinforced by their response.
The RTS standard of care was introduced in all areas where losses occurred: emergency department, day surgery, operating room, ob/gyn clinic, inpatient gyn, L & D, mother/baby, and NICU. We became experts at helping others develop support for those with miscarriages, who at the time were a forgotten population in most healthcare institutions.

The interest in miscarriage and women’s willingness to participate in a research study led to groundbreaking research done by Limbo and Wheeler—a longitudinal study of women’s experiences to the loss of their pregnancy through miscarriage.

In 1986, the first version of *When a baby dies: A handbook for healing and helping* was published. This book has been revised and updated, and it continues to be a key resource for healthcare professionals in the field of pregnancy and perinatal loss.

Resolve Through Sharing has an international presence, with programs or RTS-trained staff in all 50 states, Canada, England, Germany, Ireland, Switzerland, Japan, Italy, Guam, Spain, and the Philippines. Over 30,000 people have completed RTS educational courses.

The Bereavement and Advance Care Planning Services department at Gundersen Lutheran Medical Foundation, Inc., serves as the national office for RTS, Blueprint for Perinatal Palliative Care, Building Foundations, and Respecting Choices (a method for advance care planning).

Why do we follow up after a loss? As health care providers we know that families often feel alone after a miscarriage. As a nurse in a busy emergency department, I feel a sense of sadness whenever a woman leaves after having been told she will miscarry or that she has miscarried. Often she is alone or with one other person—scared, shocked, unable to absorb all that is being said to her. She may have felt rushed because she knows other patients are waiting and the staff is busy. Knowing that this patient will receive a follow-up call to see how she is physically and emotionally, and to guide her in her grief, is reassuring to me as her nurse. Her care is not over at discharge. Bereaved parents appreciate a relationship with someone who understands their grief and knows it does not end with the funeral or in a few short weeks after their loss (Daley & Limbo, 2008). Not every woman wants or needs intervention, but knowing that she has the option feels right.

Literature and clinical experience support follow-up care as essential to comprehensive bereavement support. Swanson’s Theory of Caring (1991) provides a theoretical underpinning for the process and content of a follow-up call. She identifies five processes of caring that include a focus on the one cared for, assessing the other’s response, being with, comforting, anticipating, informing, supporting, and offering realistic optimism. Compassion leads bereavement care and is generally thought to be beneficial, even though the effectiveness can be difficult to measure. It can seem obvious that listening to bereaved parents and offering compassion would be beneficial (Harvey, Snowdon, & Elbourne, 2008).

Joint Commission Standard PC.01.02.01, element of performance #4, addresses assessment and reassessment of aspects of bereavement care including:

- spiritual and cultural concerns identified;
- patient/family involvement/ reactions;
- environmental adequacy;
- coping mechanisms;
- respite concerns;
• bereavement assessment incorporated into the plan of care; and
• referral and further evaluation needs as appropriate.

Follow-up bereavement care through telephone calls, cards, and notes allows the RTS support person to evaluate the family’s needs and make appropriate referrals as another way to accomplish the Joint Commission standard.

In one study of parent experiences with health providers, it was found that parents valued sharing their feelings with the nurse, receiving emotional support, being treated like parents, and receiving education and information about the grief process. It was deemed helpful when caregivers could talk comfortably about the birth and loss, and there was a correlation between bereavement services offered and increased patient satisfaction (Gold, 2007). Murphy and Merrell’s study (2009) reiterates that the significance of miscarriage goes on after the hospital or clinic visit, and that bereaved women could need support and help following discharge offered by nurses or other caregivers. This implies a need for continued support through bereavement follow up.

Follow-up contacts are intended to let bereaved families know that they are cared about, especially at difficult times (e.g., anniversary or due date). Channels remain open for families to ask questions, receive support, and talk about how they feel, and to realize that their thoughts and feelings are normal. One of the most common questions grieving parents ask is, “Why are other people so cold about my loss?” It is appropriate to share that people often cannot handle grief openly and would rather turn away and ignore it (Daley & Limbo, 2008).

The following is an excerpt of conversation from a video Bereavement Services produced to educate staff using examples of questions to ask when making calls. Diane is a social worker and Heidi is a nurse. Heidi’s son Justin died when he was 7 weeks old, and these are her thoughts and memories of that time.

Diane: “Have you ever had it happen that you wake up and you think you hear Justin crying?”

Heidi: “I did have that happen, just the other night, I was sound asleep, all of a sudden I heard him and I thought, Oh it’s time for him to eat and I got up and got out of bed and went into his room, looked into his crib and it wasn’t until then that I remembered he was gone and that he wasn’t here anymore.”[Soft crying, then silence.]

Diane: “Painful reality isn’t it? You know I hear a lot of parents say that exact same thing. Sometimes they wake up and they think they hear their baby crying, they think, geez, I must be really losing it, you know, here I am, I hear my baby crying but my baby has died. That is a normal reaction that we hear a lot from parents, especially during the early weeks after the baby’s died.

In this scenario, Diane asks a question that some parents are afraid to talk about for fear that people will think they are “crazy.” She validates that these thoughts are a normal part of grief and that other people also experience them.

Diane: “Tell me about the funeral you had for Justin, what kinds of things stand out in your mind as especially important from that one day?”
Heidi: “We were able to bring all kinds of pictures down so that people could look, some people hadn’t met him, you know he was so little, so through the pictures they were able to see him, I guess ‘meet’ him. A lot of my friends came from a ways away just to be there to support me. The funeral home asked if they could do a mold of his hand. We didn’t know what that was but said yes, so we walked in and there was a mold of his hand and his fingers were curled just like they were when I fed him his bottle, so I was able to slip my finger right up in there. That was really neat and it had his little fat rolls on his wrist, so I really cherish that.

Diane: “Where do you have that now in your home? “

Heidi: “It’s in his room, on his shelf so that when I go in there I can slip my finger in his hand and it’s like he is holding it.”

Diane: “That’s a priceless item isn’t it?”

Heidi: “Absolutely.”

Diane is allowing Heidi to share her feelings—offering support and caring. By letting Heidi know that someone cares, Justin is not forgotten.

Some of the questions Diane used can be helpful in a variety of loss situations—miscarriage, feeling of empty arms, even adult loss. Recommended schedule for follow-up contacts following an early pregnancy loss is

- within 1 week;
- between 3 weeks to 4 months; and
- at the due date or anniversary date.

According to Davidson’s grief framework and the need for support (1984), recommended times for follow-up contacts following stillbirth or newborn death are

- within 1 week;
- at 3 weeks;
- at 4 months;
- at the due date;
- between 6-10 months; and
- at the anniversary date.

Realize there will be families who need and desire more than three contacts after an early loss and some who, after a stillbirth, need only one. The standard of care should be at least one follow-up contact. The RTS Manual suggests the following as one way of approaching families about follow up: “It’s routine for us to contact you sometime within the first week after you go home. Is it possible to reach you by telephone? What would be the best time of day for you?” It is important to be sure that parents are comfortable with receiving contacts and whether it is fine to leave a message. If it is impossible to phone a parent, then a note or card that includes the direct number to the RTS support person for the family to contact if needed is appropriate (Daley & Limbo, 2008).
Daley and Limbo (2008) have the following suggestions for making follow-up calls:

- Review names and events before making the call.
- Identify yourself and ask if the person is able to talk.
- Begin with non-threatening communication that does not invade privacy, “I said I’d call you this week. I’ve been thinking about you.”
- Personalize the conversation by using the names of the spouse, child, ages of siblings, recent events. Doing so increases the parent’s level of trust and barriers fall away.
- Help families anticipate what they might feel in the coming days or weeks and let them know that the phases of grief overlap.

Example of a Common Call

Diane: “I’m making my follow-up phone call from the visit you had the other day in the emergency room, wanting to see how things are going?”

This opening seems impersonal, as if it is for anyone seen in the emergency department, not for someone who has had a loved one die. It feels rushed. No names are used.

Better Example

Diane: “Hi, is this Heidi? This is Diane Midland from Gundersen Lutheran; I was the social worker with you and Eric the night that you came into the emergency room when Justin died. [Acknowledgment from Heidi.] Is this a good time to talk?

Diane acknowledges that she has met Heidi and Eric and says their names, as well as Justin’s. She acknowledges that Justin has died, that theirs was not a typical doctor visit. She checks with Heidi to see if this is a good time to talk.

When to Close Follow Up

- per RTS follow-up protocols;
- at the request of the patient or family;
- per the RTS support person’s assessment that no further follow-up is needed; or
- per the RTS support person’s assessment of the need for referral.

The feelings expressed by these women illustrate why follow-up calls are so important:

I found [the follow-up calls] helpful. It was nice to hear from someone. It made me feel better to know someone acknowledged Bryce’s life and our loss. --Brenda

I had 4 losses over 3 years and no one from that hospital ever called. I got pregnant again to try to feel better. Only after I became a social worker at Gundersen Lutheran and told someone about my losses and was contacted by the RTS coordinator did I begin to really acknowledge them. I got connected to the support group, learned about the memorial walk, and then began to acknowledge my babies. Two were boys; Daniel lived for a few minutes. I would have liked to have had that [support and information] much sooner. --Jeanne
On several occasions it crossed my mind that I would be better off with Justin than “here.” It would have helped to have someone to share those feelings with as well, and I really struggled with where to go with that. It was just incredibly difficult and consuming, and to have had someone else would have been a welcome relief. --Heidi

I really did feel like in making the video, I received my follow up phone call . . . just 11 years later. Diane did a wonderful job and even after all these years and through a scenario playing out for a video, I felt very comforted and cared for. --Heidi

To learn more about the RTS program and upcoming educational offerings, visit our website: bereavementservices.org. You can also find us on Facebook by searching, Bereavement Services/Resolve Through Sharing, click the “like” button or facebook.com/bereavementservices.

Acknowledgments

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References


COMPILATION OF GRIEF/BEREAVEMENT RESOURCES FOR HEALTHCARE PROFESSIONALS AND/OR FAMILIES

Many of these resources are adapted from the Children’s Hospice and Palliative Care Coalition website: www.childrenshospice.org

These resources are provided as a place to start your search for the specific resources your may need for the types of baby or child losses you encounter with the families for whom you care. However, you are also encouraged to contact your local community hospice that offers bereavement services and/or your local Children’s Hospital for grief/bereavement support in your area that your families can avail themselves of as they work to process their grief individually and with their families.

- **AARP** www.aarp.org/families/grief_loss
  - National Resource
  - Family, home, and legal resources regarding grief support
- **Association for Death Education and Counseling (ADEC)** www.adec.org
  - Professional organization dedicated to promoting excellence in death education, care of the dying, grief counseling, and research in thanatology.
  - Provides information, support, and resources to its international, multicultural, multidisciplinary membership and to the public via articles, books, conferences.
- **Alive Alone** www.alivealone.org
  - National Resource
  - Alive Alone is a non-profit organization that publishes a bimonthly newsletter for bereaved parents now childless and networks parents with no surviving children.
- **American Cancer Society** www.cancer.org
  - National Resource
  - Talking about cancer isn’t easy. And, there are different considerations when you’re talking to family or friends, doctors, insurance and financial companies, and your employer. Get tips on taking this important step and find communities to discuss issues you have along the way.
- **American Counseling Association** www.counseling.org
  - Mainly the United States, but also Europe and Latin America
  - The American Counseling Association is a not-for-profit, professional and educational organization that is dedicated to the growth and enhancement of the counseling profession.
- **American Family Therapy Academy** www.afta.org
  - National Resource
  - Founded in 1977, the American Family Therapy Academy is a non-profit organization of leading family therapy teachers, clinicians, program directors and policy makers, researchers, and social scientists, dedicated to advancing systemic thinking and practices for families in their social context.
- **American Hospice Foundation** www.americanhospice.org
  - Web Based
  - Articles, workshops, and links aimed at helping educators and parents provide grief support for students

- **Bereavement Publications, Inc.** www.bereavementmag.com
  - National Resource
  - Hope and Healing for the Body, Mind, and Spirit (formerly known as Bereavement Magazine) is a support group in print offering articles, stories, poems, and resources for the bereaved by grief educators and presenters, facilitators and caregivers, authors and writers, and most important the bereaved themselves.

- **Bereaved Parents USA** www.bereavedparentssusa.org
  - National Resource
  - Bereaved Parents of the USA (BP/USA) is a national non-profit self-help group that offers support, understanding, compassion and hope especially to the newly bereaved be they bereaved parents, grandparents, or siblings struggling to rebuild their lives after the death of their children, grandchildren or siblings.

- **Beyond Indigo** www.death-dying.com
  - Web Based
  - Beyond Indigo builds professional websites and provides interactive grief support services.

- **Cancer Hope Network** www.cancerhopenetwork.org
  - National Resource
  - Provides free, confidential, one-on-one support to people with cancer and their families. They match patients with trained volunteers who have themselves undergone a similar experience and provide support and hope, to help patients and families look beyond the diagnosis, cope with treatment, and start living life to its fullest once again.

- **Candlelighters for Children with Cancer** www.candlelighters.org
  - Oregon and Southwest Washington
  - Their mission is to provide support, education and advocacy to families whose lives have been affected by childhood cancer.

- **Caring Connections** www.caringinfo.org
  - The National Hospice & Palliative Care’s web-based resource to provide people with information and support when they are planning ahead, caring for a loved one, living with an illness, or grieving a loss.

- **The Compassionate Friends** www.compassionatefriends.org
  - National Resource
  - Their mission is to assist families toward the positive resolution of grief following the death of a child of any age and to provide information to help others be supportive.
  - Offers a wide variety of topical brochures related to the death of a child online for one-time use or for purchase (if multiples).

- **Compassion Books** www.compassionbooks.com
  - Web Based
  - More than 400 books, videos, and audios to help children and adults through serious illness, death and dying, grief, bereavement, and losses of all kinds, including divorce, suicide, trauma, and violence. Reviewed and selected by knowledgeable professionals.
  - Specific offerings on the death of a baby and the death of a child.
- **The Dougy Center for Grieving Children and Families** – www.grievingchild.org
  - International Resource
  - The Dougy Center is a safe place for children, teens, young adults and families to grieve
  - Also offers a wide variety of grief/bereavement-related resources for purchase.
- **Kids Aid** www.kidsaid.com
  - Web Based
  - Kidsaid is a safe place for kids to help each other deal with grief and loss. It’s a place for kids to deal with feelings in an e-mail support group, to share and view artwork and stories, and for parents and kids to ask questions and find answers.
- **Erichad** www.erichad.com
  - Web Based
  - This website labels itself “home of living support for bereaved parents” and offers articles, links, and suggested readings for grieving parents, with an emphasis on when the loss is a baby.
- **Find-A-Therapist** www.find-a-therapist.com
  - International Resource
  - Find a Therapist, Inc. is the leading Web based provider of services for mental health professionals and their clients. Since their launch on the Web in 1997, they have been offering a solution to the problem of connecting people to the right therapist at the right time.
- **First Candle** www.firstcandle.org
  - Web Based national non-profit dedicated to safe pregnancies and the survival of babies through the first years of life.
  - Offers resources for grieving families, esp. those mourning the loss of a baby who died of stillbirth, sids, or some other sudden death.
  - Also offers training opportunities/resources for healthcare professionals providing pregnancy or infant death risk reduction services or grief support to families suffering the loss of a baby.
- **GriefNet.org** http://griefnet.org/
  - Web Based
  - GriefNet.org is an Internet community of persons dealing with grief, death, and major loss.
  - Has over 50 e-mail grief support groups and two web sites which provides an integrated approach to on-line grief support for families working through grief and loss issues.
- **Grief Recovery** www.grief-recovery.com
  - United States and Canada
  - Provides Grief Recovery certification programs to those wishing to provide grief support to a community.
- **Griefsong** www.griefsong.com
  - Web Based
  - Paul Alexander’s musical resources offer a collection of songs that bring heartfelt acknowledgment, comfort and enriched meaning to the bereaved and those who travel the path with them.
• **Healing Hearts for Bereaved Parents** [www.healingheart.net](http://www.healingheart.net)
  - Web Based
  - HEALING HEARTS for Bereaved Parents is a self-help non-profit organization of bereaved parents dedicated to supporting and serving other bereaved parents and their families whose child(ren) have died no matter what the age, cause or circumstance of the death(s) by providing understanding, friendship and most of all hope.
  - Links to parent grief, infant loss, sibling grief, and grandparent’s grief, among others.

• **M.I.S.S. Foundation** [www.misschildren.org](http://www.misschildren.org)
  - International Resource
  - The M.I.S.S. Foundation is a non-profit, volunteer based organization committed to providing crisis support and long-term aid to families after the death of a child from any cause.
  - Numerous bereavement-related resources on the web for grieving families and children, and also for healthcare professionals.

• **Open to Hope** [www.opentohope.com](http://www.opentohope.com)
  - Open to Hope is a social networking website whose mission it is to support those who have lost a loved one and move into hope and healing.
  - There is a special section for grieving the loss of a child.

• **Pregnancy Loss & Infant Death Alliance (PLIDA)** [www.plida.org](http://www.plida.org)
  - Supports health-care practitioners and parent-advocates in their efforts to improve care for families who experience the death of a baby during pregnancy, birth, or infancy.
  - Provides a formal network and a unified national presence to increase awareness and education on the emotional experiences and needs of bereaved families.
  - Sponsor of National Perinatal Bereavement Conference.

• **Project Compassion** [www.project-compassion.org](http://www.project-compassion.org)
  - Non-profit that provides education, advocacy and support for all people as they deal with serious illness, death, and grief as a natural part of life.

• **Resolve Through Sharing (RTS)** [www.bereavementservices.org](http://www.bereavementservices.org)
  - A comprehensive approach to caring for families whose babies have died during pregnancy or shortly after birth.
  - This training program is now offered to healthcare professionals, in addition to other bereavement courses and a wide range of bereavement resources for families and professionals alike.

• **Share Pregnancy & Infant Loss Support, Inc.** [www.nationalshareoffice.com](http://www.nationalshareoffice.com)
  - Provides support to those lives who are touched by the tragic death of a baby through early pregnancy loss, stillbirth, or newborn death.
  - The support encompasses emotional, psychological, and social healing, as well as sustaining the family unit. Offers resources to the families and to healthcare professionals.

• **The Shiva Foundation** [www.goodgrief.org](http://www.goodgrief.org)
  - National Resource
  - The Shiva Foundation is a not-for-profit, non-sectarian organization committed to developing resources and offering support in the grieving process. These programs are offered to individuals, families and communities.

• **Webhealing.com** [www.webhealing.com](http://www.webhealing.com)
  - Web Based
  - Articles, discussion boards, and links provided to aid in the grieving and healing processes
 Cards (e.g., on the loss of a baby/child, to commemorate an anniversary of a child’s death, etc.)
Available Through:

- Memories Unlimited, Inc.  info@memoriesunlimited.com (death announcement and anniversary memorial cards)
- A Place to Remember  www.aplacetoremember.com (cards that specialize in crisis pregnancy or the death of a baby)
- A Loss Remembered  http://lossremembered.etsy.com (anniversary cards; sympathy cards for miscarriage, stillbirth, etc.)
- Greeting Card Universe  www.greetingcarduniverse.com (wide variety of sympathy cards for the loss of a baby to a child)
- Some Hallmark Card Shops also now carry a very limited selection of sympathy card(s) for the loss of a child in the Sympathy Section
Abstract: “Quilly” is a porcupine who is experiencing difficulty expressing the range of feelings he has been having since his beloved grandfather died. Quilly’s three best friends, Barby, Spike, and Pokie, are concerned about their friend who is isolating himself and resisting their efforts at support. Quilly continues to repress his feelings, and the grief comes out “sideways” through every quill in his body until he feels very heavy with grief and bristling with anger. Over time, Quilly agrees to talk with Barby, who is familiar with grief through her own loss. By sharing his story, Quilly feels lighter and less bristly. He is delighted to discover different ways he can maintain a continuing bond with memories and stories about his grandfather’s life. Other themes include the value of friendships and meaning-making in families.

Who is the audience for this information?

- Grieving children ages 4-9 years old (grades K through 4)
- Grieving families: Parents who are seeking ways to support grieving children
- Adults who work with children: School teachers, school counselors; grief counselors; clergy; those offering community grief support programs
- Thanatologists, hospice bereavement staff, and grief educators

What is special about this book? Metaphor provides a comfortable approach for an uncomfortable topic and is especially helpful for parents, adults, counselors, and educators – who may be overwhelmed themselves about approaching the topic of children’s grief. This storybook uses metaphor and a puppet to explain death and grief to children that incorporates the idea that we don’t have to say “good-bye forever.” We can maintain a connection, a bond with our loved ones even after death through the sharing of memories and special times. If we help children learn how to integrate loss at an early age they will most likely grow up to be adults who are comfortable with dying, death, and grief. The story provides a safe and secure forum for sharing feelings that otherwise may go unrecognized or become misinterpreted, thus contributing to bereavement overload and the potential for complicated grief.

Where and how can I apply this information?

This book has been used successfully within weekend “bereavement camps” offered by hospice organizations. Quilly comes to life as a porcupine puppet and speaks to the hearts of grieving children and their families. Elementary school teachers have found the book especially helpful when a child in the
classroom suffers a loss. It helps the students feel less awkward as they learn ways to support their friends at a sad time. It teaches that sadness is okay, and that over time the feelings associated with grief do subside and life can be joyful again. A Discussion Guide is included at the back of the book with reproducible activities for children and suggestions for adult/child interaction.
“Peace of mind and sense of purpose as core existential issues among parents of children with cancer.”
Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC.

ABSTRACT

OBJECTIVE: To evaluate issues experienced by parents of children with cancer and factors related to parents' ability to find peace of mind.

DESIGN: Cross-sectional survey.

SETTING: Dana-Farber Cancer Institute and Children's Hospital, Boston, Massachusetts.

PARTICIPANTS: One hundred ninety-four parents of children with cancer (response rate, 70%) in the first year of cancer treatment. Main Outcome Measure The Functional Assessment of Chronic Illness Therapy-Spiritual Well-being sense of meaning subscale. RESULTS: Principal components analysis of Functional Assessment of Chronic Illness Therapy-Spiritual Well-being sense of meaning subscale responses identified 2 distinct constructs, peace of mind (Cronbach alpha = .83) and sense of purpose (Cronbach alpha = .71). Scores ranged from 1 to 5, with 5 representing the strongest sense of peace or purpose. One hundred forty-seven of 181 parents (81%) scored 4 or higher for questions related to sense of purpose (mean [SD] score, 4.4 [0.6]). Only 44 of 185 parents (24%) had scores in the same range for peace of mind (mean [SD] score, 3.2 [0.9]) (P < .001). In a multivariable logistic regression model, parents had higher peace of mind scores when they also reported that they trusted the oncologist's judgment (odds ratio [OR] = 6.65; 95% confidence interval [CI], 1.47-30.02), that the oncologist had disclosed detailed prognostic information (OR = 2.05; 95% CI, 1.14-3.70), and that the oncologist had provided high-quality information about the cancer (OR = 2.54; 95% CI, 1.11-5.79). Peace of mind was not associated with prognosis (OR = 0.74; 95% CI, 0.41-1.32) or time since diagnosis (OR = 1.00; 95% CI, 0.995-1.003).

CONCLUSIONS: Physicians may be able to facilitate formulation of peace of mind by giving parents high-quality medical information, including prognostic information, and facilitating parents’ trust.
Who is the audience for this information? All members of the health care team. It will be particularly helpful for physicians who, because of worry over impact on the parents of hearing bad news, may avoid delving into specific information about the disease and the prognosis.

What is special about this article? It is nice to understand what the parents perceive from the communications of the health care team. While there was a moderate degree of sense of purpose, parents reported low degrees of peace of mind. Parents report being more hopeful after a conversation that includes prognostic information, even if the prognosis is poor. Interestingly, likelihood of cure was not related to the parents’ peace of mind, but information quality, trust, and prognostic disclosure were.

Where and how can I apply this information? Physicians can feel more confident that prognostic disclosure will help rather than hinder parents’ peace of mind. Delivering this information may lead to less uncertainty on the part of the family and may be associated with less use of non-beneficial life supporting technology at end of life.
READERS CORNER

Amy Kuebelbeck and Deborah L. Davis, PhD

A Gift of Time:
Continuing Your Pregnancy When Your Baby’s Life Is Expected to Be Brief
(Johns Hopkins University Press, January 2011)

We both desired that Nathaniel complete his journey with dignity and love. I knew I would carry this child and mother him the best I could as long as he lived and grew within me. But I still had to walk the road between the decision and the delivery. I was determined to honor his life and prepare to say goodbye and release him the best way I knew how. —Annette

When prenatal testing reveals that an unborn child is expected to die before or shortly after birth, some parents will choose to proceed with the pregnancy and to welcome their child into the world. A Gift of Time is a gentle and practical guide for parents who are (or are considering) continuing their pregnancy knowing that their baby's life will be brief. With compassion and support, A Gift of Time walks them step-by-step through this challenging and emotional experience—from the baby's life-limiting prenatal diagnosis and the decision to continue the pregnancy to coping with the pregnancy and making plans for the baby’s birth and death.

A Gift of Time also offers inspiration and reassurance through the memories of numerous parents. Their moving experiences are stories of grief—and of hope. Their anguish over the prenatal diagnosis turns to joy and love at the birth of their child and to gratitude and peace when reflecting on their baby’s short life.

Based on material from more than 100 parents from across the U.S., Canada, Europe, and Australia, A Gift of Time draws extensively from parent experiences and includes many direct quotes that tell powerful stories. Full of practical suggestions for parents and for caregivers, it also features the innovative concept of perinatal hospice/palliative care. Caring and thoughtful, the book helps parents embrace the extraordinary time they will have with their child.

I didn’t voluntarily return her to God; I had no choice. I did have a choice in how I could love her, honor her, share our journey and her life with those people that we loved and knew us. We are all better for having followed our daughter’s lead in this story. She was a gift and I am grateful, every day, that we allowed ourselves to receive it. —Alessandra

Amy Kuebelbeck, a former reporter and editor for The Associated Press, is the author of the memoir Waiting with Gabriel: A Story of Cherishing a Baby’s Brief Life and editor of www.perinatalhospice.org. Deborah L. Davis, Ph.D., is a developmental psychologist and expert in the emotional aspects of neonatal medical ethics and perinatal bereavement. She is the author of Empty Cradle, Broken Heart: Surviving the Death of Your Baby.

A Gift of Time is available directly from the publisher at (800) 537-5487 or the publisher’s website, Amazon.com, Amazon.co.uk and other booksellers. Bulk rates are available by calling 410-516-6936 or e-mailing tjl@press.jhu.edu.
Items of Interest

In each issue of our ChiPPS e-newsletter, we offer additional items of interest. Please remember, information on the resources below and an archive of past newsletters is available at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).

1. **Concurrent Care for Children Requirement Implementation Toolkit.** On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act into law enacting a new provision, Section 2302, termed the “Concurrent Care for Children” Requirement. The District of Columbia Pediatric Palliative Care Collaborative and the National Hospice and Palliative Care Organization are pleased to provide the **Concurrent Care for Children Implementation Toolkit**, which details information on the options available to states who are implementing Section 2302 or are considering expansion of pediatric palliative care services to children living with life-limiting or life-threatening conditions.

The Toolkit can be used as a guide to: understand the impact of the CCCR on state Medicaid programs; consider the different Medicaid state plan amendment and waiver options available to states; review examples of existing comprehensive palliative care programs for children in states that have implemented such programs; and learn how to develop a coordinated, collaborative state-wide approach for advocating for children with life-threatening conditions through a comprehensive array of services. The **Concurrent Care for Children Implementation Toolkit** is available for download free of charge on the NHPCO website.

2. **Pediatric Palliative Care Online Courses Available.** NHPCO’s Pediatric Palliative Care Online Training Series provides instant access to educational resources for pediatric care providers. The series offers 10 online educational modules written by leading pediatric palliative/hospice care experts across the country and will be available through NHPCO’s E-Online in 2011. Two of the ten modules are now available – **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. Download the **Pediatric Palliative Care Course overview** (PDF) and when you’re ready to take these offerings, you can access the online modules via NHPCO’s E-Online education portal.

3. **Pediatric Palliative Care Patients: A Prospective Multicenter Cohort Study.** An article published this week in the professional journal *Pediatrics* (*Pediatrics 2011; peds.2010-32250*), is the first cohort study examining the characteristics and survival of children receiving hospital-based palliative care. The study highlights the differences between adults and children needing end-of-life care and should help instruct hospitals looking to establish their own pediatric palliative care teams. Researchers that included Chris Feudtner, MD, and ChiPPS co-leader and NHPCO’s Pediatric Medical Consultant Sarah Friebert, MD, found that children with life-threatening illnesses receive hospital-based palliative care services for an average of more than a year, far longer than adults who require similar end-of-life support. The **article abstract** is available online at the *Pediatrics* website.

4. Two resources are now available from ACT (Association for Children's Palliative Care) in the United Kingdom. *A Care Pathway to Support Extubation within a Children’s Palliative Care*
5. Pediatric Intensive at 2011 Clinical Team Conference. NHPCO's 2011 Clinical Team Conference, will be held in San Diego, California from October 6 - 8, 2011 at the Town & Country Resort and Convention Center. The conference theme is “The Hospice IDT: Leading and Innovating Quality Throughout the Care Continuum.” Visit the link above and receive Early Bird Registration and discount pricing through June 17, 2011.

6. Standards of Practice for Pediatric Palliative Care and Hospice Receive AAP Affirmation of Value. As reported previously, NHPCO Standards of Practice for Pediatric Palliative Care and Hospice (Standards) has 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.

Standards of Practice for Pediatric Palliative Care and Hospice is available in downloadable format, free-of-charge to NHPCO members. The Standards also are available for purchase from NHPCO's Marketplace at a nominal price (item #821399).

7. Subjects and Contributors for Future Issues of This Newsletter. In past issues of this newsletter, we have addressed a wide range of subjects, including bereavement, sibling bereavement, self care, ill and dying teens, perinatal loss, neonatal loss, spirituality, unsung heroes in the circle of care, pain and symptom management for children with life-threatening illnesses and their families, families experiencing transitions associated with pediatric palliative care, complementary therapies, examples of programs illustrating the current status of pediatric palliative and hospice care in the United States, memory building and legacy making in pediatric palliative and hospice care, examples of many programs offering this type of care in various parts of the world outside the United States, and ethical issues related to pediatric palliative and hospice care. (Please note that you can visit archived issues of this newsletter online.)

For future issues, we are thinking about addressing subjects such as moral distress, staff stress, and personal or organizational care. If you know of good topics and/or contributors (including yourself) for any of these and/or other future issues of this newsletter, please do not be shy! Step right up and contact any of the following: Christy Torkildson at torkc@sbcglobal.net; Maureen Horgan at Maureen.Horgan@providence.org; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

8. Reader's Corner. Our Reader's Corner column provides brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric palliative care, but that may not be known to all readers of this newsletter. Contributions to the Reader's Corner, like the ones in this issue, include an abstract of the publication, a description of the audience for this information, comments on what is
special about the publication, and suggestions as to where and how this information can be applied. We welcome suggestions for publications to include in our Reader’s Corner and/or summaries and comments on such articles following the model in this issue. Please send all such suggestions to Christy Torkildson at torkc@sbcglobal.net.

9. Calendar of Events. As a reminder, there is a Calendar of Educational Opportunities on the NHPCO website. You can submit an event using the online form or email information to Christy Torkildson at torkc@sbcglobal.net to have a pediatric palliative care educational offering listed.

10. Complete Two MDP Levels in Three Short Months Without Leaving Home. Like many hospice professionals, you’ve probably invested a lot of time learning new clinical skills. But how much time have you invested in developing your management skills? Whether you are currently a hospice manager or are hoping to be one, NHPCO’s Hospice Manager Development Program is the only management training designed by hospice leaders, for hospice leaders. For the first time ever, you can complete Levels I and II of our highly-acclaimed Hospice Manager Development Program (MDP) in less than three months – without leaving town! If you are interested in developing your managerial skills, learn more about NHPCO’s MDP Summer School.

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

Thank You

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

If you are not on our mailing list and received this newsletter from a friend or some other source, please complete our sign up form. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460.

Visit the ChiPPS web page at www.nhpco.org/pediatrics for further materials and resources of interest.