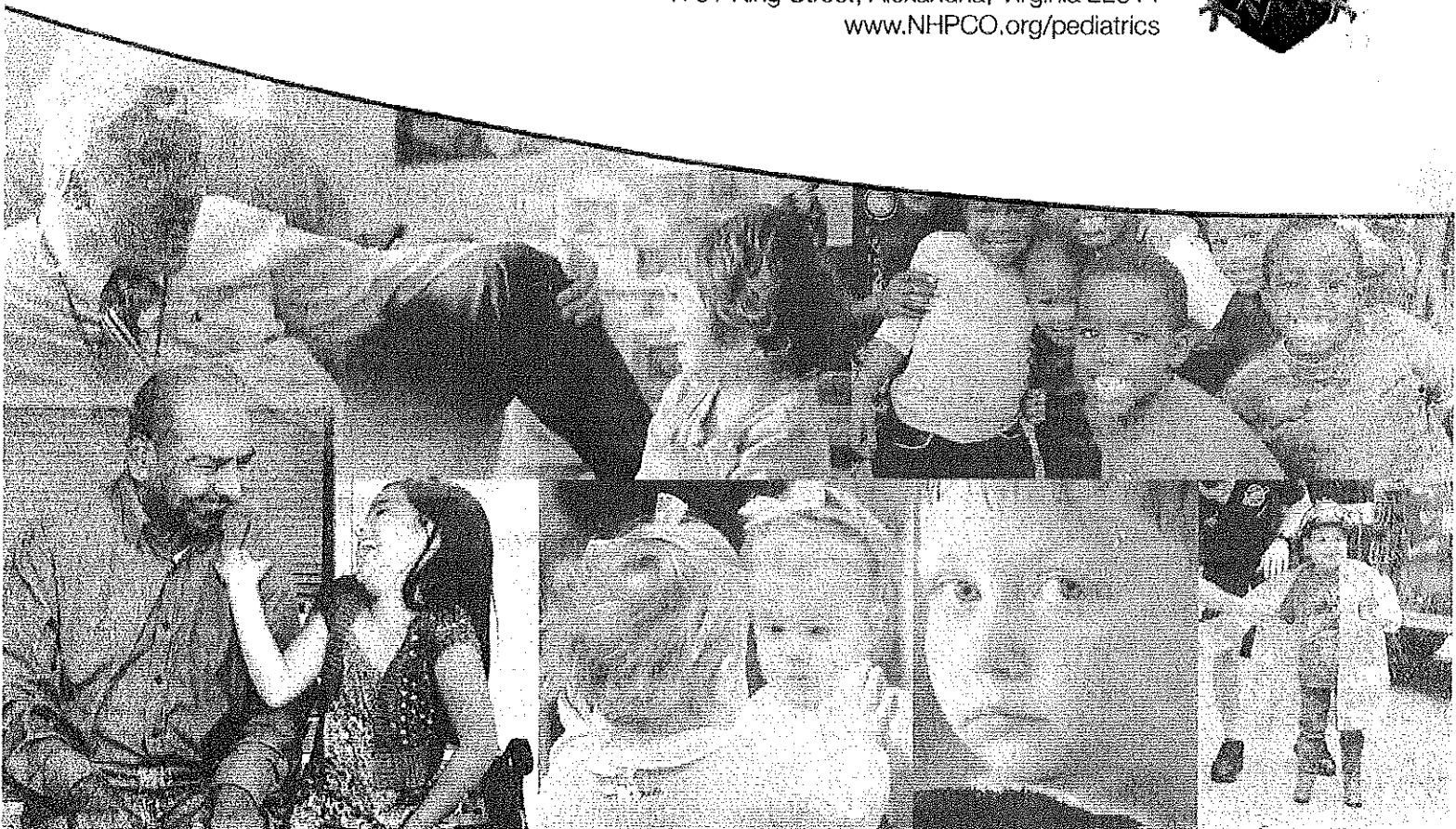
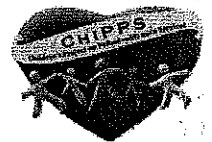


**Selected Issues Arising Near, At, or Following the Death of a Child**  
**Issue #35; May, 2014**

# ChiPPS E-Journal

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

National Hospice and Palliative Care Organization  
1731 King Street, Alexandria, Virginia 22314  
[www.NHPCO.org/pediatrics](http://www.NHPCO.org/pediatrics)



## Issue #35:

### Selected Issues Arising Near, At, or Following the Death of a Child

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

#### *Two Poems*

p. 4

#### **Noah Newport**

Noah is the son of our "resident poet," Scott Newport, whose contributions have appeared in many issues of this E-Journal. Here Noah shares two poems, one about the "last breaths" of his brother, Evan, and the other about himself.

#### *My Time to Cry*

p. 5

#### **Anne Ryan**

Anne is the mother of Mitchell, who was born with a life-threatening condition. Here Anne describes some of their experiences during the five years before Mitchell's death. She also praises some of the professionals who took part in caring for Mitchell.

#### *The Little Boy on the Wall of Courage*

p. 8

#### **Colton Radenbaugh**

Colton is Mitchell's brother and Anne's other son. In this article, Colton reflects on Mitchell's life, the care he received from Anne and many professionals at a children's hospital, and Mitchell's death. Colton explains what the children on the Wall of Courage and their family members need from professional care providers.

#### *How to Talk to a Parent Who has Lost a Child. From Someone Who's Been There.*

p. 10

#### **Samantha Hayward**

After the death of her daughter, Ella, Samantha reports that she had "been surprised by people's genuine kindness and empathy as much as I've been repeatedly shocked & disappointed by their lack of it." In this article, she offers "ten things I wish people knew about the loss of a child. Maybe one of my ten points might make a difference to a bereaved parent's life."

#### *Caring for Surviving Children before, during, and following the Death of a Sibling:*

#### *A Funeral Director's Perspective*

p. 15

#### **Patrick E. Lynch & Brigid G. Lynch, MA, LPC**

In this article, Patrick and Brigid offer the perspective of funeral service providers when there are siblings in a family that experiences the death of a child. The authors recommend that "Parents, no matter how difficult it is, must attempt to address the sadness, fears, and other feelings of the remaining children in the family." This includes involving children in the care of their sibling, time alone in conversation, and open dialogue before, during, and after the death occurs. Finally, the article observes: "The common theme associated with children's funerals seems to be allowing, even encouraging, familial participation. In this way, family members including children are able to 'do' something of purpose at a time when doing anything at all seems an impossible concept."

#### *Let Us Touch: Palliation and the Physical Exam at the Time of Dying*

p. 18

#### **Emily Riegel, MD, FAAPMD, FAAP**

The author notes that when a child is near death, professional care providers often "have our own concerns about causing more distress, pain, or discomfort . . . Still, when parents are willing, doing a physical exam and offering physical touch and comfort can be 'an act of normalization,' a sign that their daughter, even with a terminal condition, still deserved full attention and consideration. It meant she wasn't just being 'written off' because she carried an extra chromosome. It meant she mattered, and that she was an individual who should be seen and known as such, rather than only being judged based on her diagnosis." Examining and holding a child can model good care for many parents. By contrast, "When the exam is not done, when their child is not touched, it signals that their child does not deserve the same kind of care as a 'normal' child. It may signal a lack of concern or care, or even a fear, of the child."



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*Last Hours: The Most Tender of Journeys*

p. 21

**Pamela Mange, RN, CHPPN**

In this article, an experienced pediatric hospice nurse offers nine points in a program of best practice to help prepare families for what could or is likely to happen when a child is imminently dying. She also writes about the great value of being present at the time of death, if at all possible—"Parents never forget that final moment"—and of following up afterwards.

*When the Time Comes: Little Things Really Matter**When the Time Comes: How to Help When a Child Dies in the Home*

p. 23

**Liz Sumner RN, BSN, MA ORGL**

In these two articles, an experienced pediatric hospice nurse explores some of the many "little things" that can matter a great deal near, at, or around the time of the death of a child. The first article describes suggestions to offer to a family, rituals at the time of death, creating keepsakes of various types, and some of the many transitions that are likely to occur. The second article presents these and other suggestions in the form of 11 bulleted points. Both articles emphasize situations involving the death of a child at home.

*Guidelines for Care and Caring at the End of a Child's Life**Checklist for Care and Caring at the End of a Child's Life*

p. 28

**Suzanne S. Toce, MD, FAAP**

These two articles set forth a set of nine detailed guidelines around which to organize care at the end of a child's life. The first article offers nine "prompts to encourage discussion and planning" along with examples of scripts for how to foster dialogue. The second article reduces the main points of the guidelines to a simple checklist. The underlying lesson is that "there should be a plan, regular review/update of the plan, and review to ensure compliance with the plan."

*Shining the Light: End-of-Life Care Focus in Pediatric Oncology*

p. 35

**Claire Vesely RN, BSN, CHPPN**

This article gives special attention to issues that often arise in pediatric oncology when a child's death is imminent. Its goal is "to improve the anticipatory guidance given to families of what to expect" by reframing symptoms, explaining decreases in pharmacology and medical interventions, dispelling confusion about blood transfusions, foreseeing the possibility of a pre-death rally (sometimes called "The Last Good Day Convention"), and explaining palliative sedation, if appropriate. The article concludes with a brief discussion of simple strategies well known to palliative care teams that can be helpful to parents at the end of their child's life.

*Medication Considerations at or surrounding a Child's Death*

p. 38

**Melissa Hunt, Pharm.D.**

We are pleased to include in this issue what we believe is the first detailed discussion of pharmacological issues in this E-Journal. Melissa provides a detailed exposition of sublingual and rectal routes of administration of medications near the end of life, as well as common hospice medications that are appropriate for each of these routes. The article also explores discontinuing medications as patients approach the end of their lives and weaning off medications. Also discussed are the value of comfort care kits and disposal of unused medications.

*Two Documents from the Pregnancy Loss and Infant Death Alliance (PLIDA)*

p. 42

We conclude this issue with two documents from PLIDA. These are a practice guideline about "Offering the Baby to Bereaved Parents" and a position statement on "Delaying Post Mortem Pathology Studies." We reprint these documents (with permission) because we believe they offer practical and helpful advice to readers. In so doing, we note that while the first of these documents is framed in terms of very young children, much of its contents are applicable to situations involving any bereaved parent.

*Items of Interest*

p. 53

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

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## TWO POEMS

**Noah Newport**  
 Brother of Evan  
 c/o [scottandpenni@hotmail.com](mailto:scottandpenni@hotmail.com)

### His Last Breaths

The beeps just kept coming  
 As the fun free feeling was numbing  
 I could not let go  
 My hands were noodles  
 For his heart was starting to slow  
 His grip was growing weak  
 As my eyes started to leak  
 His last breaths were silent  
 The doctors could not do anymore treatment  
 He has now passed  
 It happened all too fast like a guns blast  
 For him to be my brother I was thankful  
 Now he is somewhere better with an angel.

### Noah,

Loving, caring, giving, and smart,  
 Brother of Evan and Chelsea,  
 Lover of football, ice cream, and family,

Who feels sadness when you lose someone you love,  
 Excitement when you get on the  
 Football field, joy when you're with your family

Who needs your parents, sports, and a home  
 Who gives inspiration, support, and toys to the poor  
 Who fears losing something close to you  
 Heights and the end of the summer  
 Who would like to see earth from space  
 The pyramids and the world's largest tree

Who lives in one of the only two story houses on Samoset St  
 And has a baby tree  
 Just trying to grow big  
 Newport

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## MY TIME TO CRY

**Anne Ryan**

Bereaved Parent & Vice President, here4U, Inc.

[anne.katherine@me.com](mailto:anne.katherine@me.com)

This morning my oldest son, Cole, sent me a text. It said, "Visited our favorite little boy today<sup>6:58</sup>. The attachment was a picture of my youngest son's gravestone. It was surrounded by a blanket of fresh snow. I live in Georgia now, where there is no snow, and I suddenly felt a million miles away from my heart.

I was at work when I read it, and I just wanted to cry. That seems fair, right? But I didn't. I put my phone aside and pulled myself together. It's been three and a half years since Mitchell died, yet random moments like this sometimes punch me in the gut. They come out of nowhere, with no warning, and despite what everyone tells you, it never gets easier.

My son, Mitchell, came rushing into this world on May 20, 2005, sixteen weeks premature, in a whirlwind of tubes, needles, ventilators, and medication. From the day he was born, Mitchell was a fighter. He overcame obstacles that doctors never thought he could, and when I finally brought him home from the Neonatal Intensive Care Unit, I knew Mitchell would do great things. But I had no idea that it was the "how" he would do great things that would be the most profound.

When he was one, he was diagnosed with severe spastic quadriplegia, a form of Cerebral Palsy. I was told he would likely never walk, talk, or feed himself. I immediately mourned the little boy he would never be. No baseball games, no riding a bike, no talks about girls. I was brokenhearted for him...and for me. But he wouldn't let me feel that way for very long. All I had to do was look into those big green eyes, feel the warmth of his hand holding mine, and I knew he was happy just the way he was. He didn't want to live life any other way. He was perfect.

I spent the next five years being taught how to live by a sweet little boy in a bright blue wheelchair. He taught me about courage, and how to be passionate about the things that are important to me. He taught me how to take risks and to never tell myself I couldn't make it. I never would have imagined that a tiny little boy would have such a profound impact on my life. But he did.

Because of Mitchell I met many new people...doctors, nurses, therapists, and teachers. All of Mitchell's specialists were at Mott Children's Hospital at the University of Michigan, and we traveled back and forth a couple times a month from the southwest corner of the state so they could tend to his many needs. I worked tirelessly to educate myself about his condition and the many problems that surrounded it. All along, the doctors and nurses that cared for Mitchell became the rock that I leaned on. They offered me ideas, support, and respected my decisions. Most importantly, they showed my son the love and respect any child deserves; especially a child with special needs.

Mitchell thrived. He attended school where he made me little paintings and art projects, he went on field trips, and he was learning to communicate. We went for countless walks on the beach, he loved eating anything and everything, he was crazy about his cartoons, and he always had a smile for all the people who came to know and love him (and those he met for the first time).

At the beginning of 2010, Mitchell began to change. Things happened subtly at first, so subtly that I didn't



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notice right away. He wasn't his usual happy self. He didn't laugh as much as he used to. I began to get more and more calls from school telling me he wasn't feeling well. We made many trips to the doctor and they all came up empty. Nothing was really wrong with Mitchell, he just wasn't himself. During the summer of that same year, Mitchell started having trouble breathing, and after a couple of 911 calls and subsequent visits to the local ER where he was stabilized and sent home, Mitchell was finally rushed to Mott Hospital. He was very sick. Not the immediately diagnosable sick, but the twisted in pain, respiratory distress, can't find a reason why kind of sick. Me and my fragile little boy spent two months in Mott's PICU trying to figure out what was wrong, while Mitchell was trying to tell us it was his time to die—something I never wanted to hear and tried my best to ignore.

No stone was left unturned, no test was overlooked. For those long two months, Mitchell and I were treated like we were part of a family. A family that was pieced together from many different roles. We were parents, doctors, nurses, social workers, and many, many more. We laughed, we cried, we rejoiced, and we reflected. I taught them about Mitchell, they taught me about medicine, and together we learned about life. We, as a team, worked tirelessly to try and heal my poor sick boy. In the midst of everything, Mitchell was teaching us how to be better people. He taught us what it means to be a fighter. He taught us that you can find love, strength, and hope in the saddest places, and he taught us that you don't always have to survive to make a big difference.

On October 3, 2010, although Mitchell couldn't talk, in my mind, I finally heard the words that he had been trying to tell me for months, "Mommy, I'm done. I came here to make a difference and I did. Now I have to go." I never questioned those words, never doubted them, but they hurt. In the end, I realized that he had given me, and so many others, the greatest gift: the gift of knowing him, loving him, and learning from him. Later that day, I sat in a family meeting with all his specialists. I was a single mom, and although I was doing this by myself, I wasn't alone. I told my "family" what Mitchell wanted. No one said a word. It was like he had told them, too, and I had been the first to say it out loud. These people, who had worked tirelessly for months, lost sleep, came in on their days off to heal my boy, had finally realized, too, that Mitchell had accomplished what he came here to do. He brought us together, made an impact on our lives, and now he was giving us the ability to help others. You see, when a child like Mitchell comes along, you are never the same. You look at the world differently, you look at people differently, and you look at life differently.

One of the PICU fellows that had cared for Mitchell from the beginning came around the table to my chair. I was still sitting there thinking about the monumental decision I had just made, when he dropped to his knees and took me by the hand. He told me that I had made the most selfless decision he had ever seen a parent make. He told me that I was absolutely doing what was right for my son. Then he asked if he could do one more thing for Mitchell. He wanted to make sure that my boy didn't suffer. He called the pain management team to come make Mitchell as comfortable as possible as he spent his last hours with us.

I went to the room where I had spent the last several months praying for a miracle, lifted my son out of his bed, and buried my face in his neck. Slowly, staff started trickling in. Some to remove the many tubes and needles from his body, some to come say goodbye, and some to just sit and reminisce about the boy they had come to love.

Mitchell took his last breath, in my arms, on October 5, 2010, surrounded by a half dozen doctors and nurses.

Some might think that having your child die in the hospital is sad. That maybe it's cold and impersonal.



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But let me tell you, that isn't always true. I wouldn't have had it any other way. Everyone is different. We are all comforted in different ways. I was comforted by the fact that I was with people that loved my son, and who loved me. We were with people who worked as hard as they did to heal him as they did to help me survive. The doctors and nurses that cared for us will forever be in my heart. Most are still a part of my life all these years later.

When I got home from work tonight, I took out my phone and reread my text from Cole. I cried. And that's okay. I miss my sweet Mitchell, and I always will.

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## THE LITTLE BOY ON THE WALL OF COURAGE

**Colton Radenbaugh**

Brother to Mitchell Miller Ryan  
Student at Michigan State University  
[colton.radenbaugh@icloud.com](mailto:colton.radenbaugh@icloud.com)

October 5<sup>th</sup> 2010 is day that I will not forget not only because of what happened, but also because of how much it made me realize how thankful I was to have had Mitchell as a little brother. On that day, I came to understand how much Mitchell had been such a pivotal part of influencing and making me the person I am today, without ever uttering a single, comprehensible word. Never would I have expected that someone so small and innocent would be able to teach me about life, death, and the importance of family, by simply being here.

I was in my hometown of St. Joseph, Michigan, and had been for the entirety of Mitchell's last visit to the Mott Children's Hospital at the University of Michigan. While my mother was gone to stay with Mitch at the hospital, which was on the other side of the state, I had been charged with looking after my little sister, Hanna, and our house. As a senior in high school, responsibility was something I was accustomed to. Though I was extremely busy during this part of my school year with football, extracurricular groups, and AP classes, I knew how much it meant to my family for me to be able to fill in for my mother when this unfortunate hospitalization with Mitchell came about. Even if Mitchell took up a good amount of our mother's time prior to this, she still tried as hard as humanly possible to always make it out to our sporting and school events—even taking Mitchell out to support us, as he was the biggest little fan our school team, The Bears, had that year. Every one of our friends' parents and family members knew who the cheerful little boy in the wheelchair was at those games.

On the day of Mitchell's death, it was a Tuesday, I had been woken up by what I thought was my alarm, but instead, it turned out to be my mother calling me. I answered the phone and instantly could tell from the delivery of her first word that this was the call; Mitchell was going to pass away. She told me to ready my sister and myself, because our Aunt Janet was going to pick us up to go to Mott. I had a moment of disarray as I tried to get my sister up and ready us for the arrival of our Aunt. I'd known Mitchell was sicklier this time around than any other before, but he had always pulled through these rough bouts with his health ever since he was born. I had become so used to him being the tough little boy who could beat any odds, that I didn't think it would ever come to us having to say goodbye. This mindset, that had made me take for granted the resiliency of my brother, was one of the biggest regrets that I had.

Goodbye, this was the only thing that I could think of the entire ride across the state to Ann Arbor. All I wanted in that moment was to be able to say goodbye to my special little brother and let him know how much he had done for me in his short time with us. It was important to me that he wouldn't pass away alone, as he always seemed to enjoy life a little more when all of our family was around him and we were together. Being by his side one last time was the one thing that I was hoping for, that we would have that chance to say goodbye peacefully.

Once we had arrived to Mott, our mother, who was waiting for us in the lobby, met us. I had seen my mom many times before in hospitals and some of those times in terrible dejection, but this was not one of those times. Her face had sorrow on it, but she looked more at peace than what I had seen in the past. I knew that she had been well taken care of and the same for our brother.

As we made our way up to the PICU where Mitchell was, we passed a wall with pictures of lovely-looking children, all happy and full of life, with a short little story of their time on this planet. This was the Wall of Courage, dedicated to the wondrous kids who had been there before, but who were just taken from the world too soon. I remember feeling after passing that wall, that these doctors and nurses in the PICU really cared about the children they were helping. I knew that they, too, would walk past that wall every day and remember the lives of the children that had been walked or wheeled through this wing but who



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were no longer here. I remember thinking that even if these children weren't remembered by others, they would never be forgotten by the people who had helped care for them. This left a powerful impact on me.

While my mother had to endure most of the two-month long ordeal leading up to Mitchell's death alone, I knew after seeing her in the lobby, that she had more support in that time than she had in a hospital before. She spoke of nurses and doctors in the PICU who had been with her every step of the way—not only including her in every decision and conversation about Mitchell, but also becoming a little part of our family. How they listened and learned from her about Mitchell from late nights and long talks, and about how much he meant to us. I met some of these specialists during my last time with Mitchell and instantly I could tell that they were a caring and thoughtful group. When I met Mitchell's primary nurse, she already knew so much about me from talking and listening with my mother, that I could feel a sense of comfort with her; similar to a long-time friend. The sensation of understanding and emotional support of family was all that I could feel after meeting most of Mitchell's attendings, though I had never met any of them before. They gave this doleful and unfortunate event a small feeling of peace.

Being a good physician, especially in the impending death of a loved one, is not always about trying and doing everything you can to help treat the dying family member. It's also about caring for the family, too. When a group of loved ones are experiencing this, the thing I would say to any doctor is to act human; show some sympathy and vulnerability to the family. Let them know you are more than just a tool of healthcare that looks for ways to cure people, but also an equal in the outcomes of life. The comfort of someone being there, so that a person might not have to cry alone or recollect on the life of the passing on their own, can be invaluable to some people. This type of integrity and caring that my mother and little brother received is something that I am ever grateful for from the team in the Mott PICU. Mitchell was the biggest little lesson that I have ever experienced in my life and I will always miss him.

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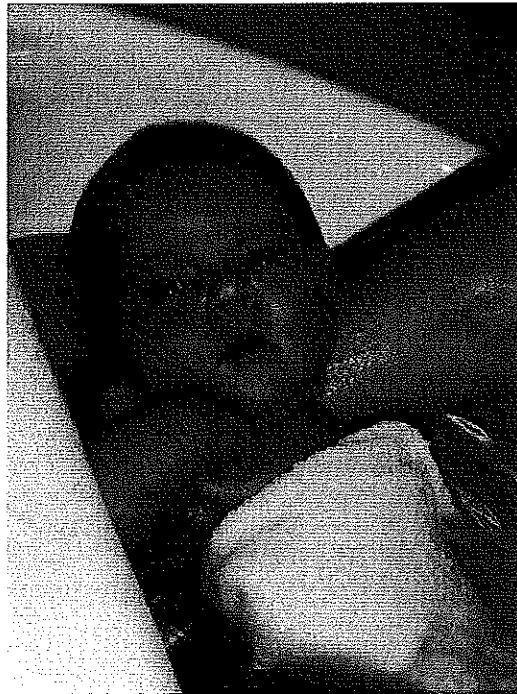
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## HOW TO TALK TO A PARENT WHO HAS LOST A CHILD. FROM SOMEONE WHO'S BEEN THERE.

**Samantha Hayward**  
[Samanthahayward1975@hotmail.com](mailto:Samanthahayward1975@hotmail.com)



Ella Nicole Hayward

The soul destroying agony of your child dying is only truly known and understood by those who have endured it. Four years on, I still glance down at my daughter's grave in disbelief. Visiting my child's grave is surreal. It's almost like I've vacated my body and I'm watching someone I don't know standing there putting flowers down.

Is this really my life?

Only a parent understands the powerful bond you have with your child; that absolute undying love you have and that monumental desire that roars like an open fire inside you to protect that child at all costs. It is openly said that a parent will lay down their life for their child, but it is not until you have your own that you truly understand these fierce emotions. Parenting is wearing your heart on the outside of your body. Whatever you imagine it might be like to have your child die, multiply that by about a trillion and you're probably not even close.

On the surface it appears society is accepting of this unbearable sadness and people are supportive and open to talking about it. However, in my situation I've been surprised by people's genuine kindness and empathy as much as I've been repeatedly shocked & disappointed by their lack of it. It's necessary for bereaved parents to be able to talk and, most of all, be able to talk openly. I've found it's the only thing which dispels the trauma.

Sure, friends and family have been supportive, but it's proven to be the case with me that there is a



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mandate as for how long their unwavering support, patience, understanding, concern and empathy lasts. The truth is the situation is so unbearably sad that it becomes incredibly emotionally draining on the other person.

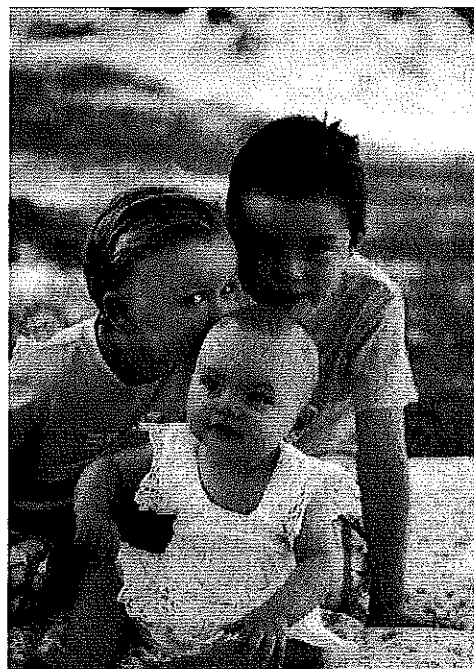
The realization that they can't fix your sadness sets in, the frustration builds because not even they can see an end in sight, then gradually it starts to impede on the happiness in their life. They haven't lost their child so why should they spend all their time sad about yours?

I will, for the sake of all the other parents out there with empty arms, write ten things I wish people knew about the loss of a child. Maybe one of my ten points might make a difference to a bereaved parent's life.

1. **Four years on I get up every day with the exact same sadness I had the day Ella died.** The only difference is I'm more skilled at hiding it and I'm much more used to the agony of my broken heart. The shock has somewhat lessened, but I do still find myself thinking I can't believe this happened. I thought that only happened to other people. You asked how I was in the beginning yet you stopped, why? Where did you get the information on what week or month was good to stop asking?
2. **Please don't tell me that all you want is for me to be happy again.** Nobody wants that more than I do, but it's something that can only be achieved with time. On top of that, I have to find a new happiness. The happiness I once felt, that carefree feeling will never return in its entirety. It also helps to have the patience and understanding from loved ones.
3. **Please don't say 'I want the old Sam back!'** Or, I can see the old Sam coming back! Sam's not coming back. This is who I am now. If you only knew the horror I witnessed and endured, you would know it's not humanly possible for me to ever be the same person again. Losing a child changes who you are. I've been told my eyes look haunted.

It's a strange thing for someone to tell a grieving mother, but it's true – I am haunted. My views on the world have changed; things that were once important are not now and vice versa. I feel as though you're telling me two things here. Firstly you don't like the person I am and, secondly if the old Sam's not coming back I'm out of here. By the way there is nobody that misses the "old Sam" more than me!! I'm mourning two deaths here; my daughter's and my former self.

4. **If you chose to acknowledge my daughter's birthday or the anniversary of her death on the first year, it's terribly gut wrenching when you didn't bother to acknowledge the second or third or fourth.** Do you think any subsequent birthday or anniversary is not as sad for me? It also says to me in very big neon lights that you've moved on and forgotten about my daughter.
5. **Please stop with the continual comments about how lucky I am to have my other children particularly my daughter.** Do I say this to you? Then why say it to me? I've buried my daughter; do you seriously think I feel lucky?
6. **It's not healthy to cry in front of the kids?** You're wrong. It is perfectly healthy that they see I'm sad their sister has died. When someone dies it's normal to cry. What would not be normal would be for my children to grow up and think "I never even saw my Mum sad over Ella's death." That would paint me in a light that would tell them it's healthy to hide your emotions when obviously it's not.



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**7. I have four children I don't have three.** If you want to ignore Ella as my third child because she's dead go for it, but don't do it for me. Four not three!

**8. There are still some days, yes four years on, that I still want to hide away from the world and take a break from pretending everything is oh so wonderful and I'm all better.**

Please don't just assume I've thrown in the towel, or worse, actually be so thoughtless as to wonder what's wrong with me. I still know I've married the catch of the century and my children are gorgeously divine and I have a beautiful house, but I'm grieving.

It's mentally exhausting, especially raising three young children and on top of that maintaining a strong and loving marriage. Unbeknownst to you, I'm dealing with not just my own grief, but my beautiful husband's and my two boys.

It would be nice if you congratulated me on the state of my family because keeping it together, stable and happy, has been hard work.

**9. I did notice.** To the friends and family that found the entire death and dealing with my sadness all too hard and held secret events behind our backs that were lied about, stopped inviting us to things we had always been included in and slowly ended our relationship thinking I didn't notice.

I did notice. The only reason why I never said anything is because I'm not wasting my words on your shameful behavior. I am thankful for something though – I didn't waste any more time on people that were capable of such shallowness and cruelty. Please don't fear. I would be the first one by your side if the same thing happened to you. That should give you some indication of how horrible it is.

**10. Grieving for a child lasts until you see them again.** It's a lifetime. If you're wondering how long your friend or family member might be grieving for, the answer is forever. Don't rush them, don't trivialize their sadness, don't make them feel guilty for being sad and when they talk to you, open your ears and listen, really listen to what they're telling you. It's possible you'll learn something. Don't be so cruel as to give up on them; remember it's not about you, it's about them.

I've been left repeatedly heartbroken as friends that I truly loved and never thought would walk away from me tossed me into the too hard basket or – more hurtfully – the crazy basket. Phone calls stopped, text messages stopped, comments on Facebook stopped and I get the same thing every time. "Sorry darling I'm just flat out," "Let's catch up soon" and "I miss you." The list could keep going but I get it. I'm not the type of person either that is going to pursue a friendship I know the other person doesn't want. Everyone has a conscience and thankfully I don't have to live with theirs.

You would think there are a lot of articles that raise awareness of the awful process associated with grieving for a child, but even stories from other parents are a rarity. The sad reality is there just isn't enough said or printed. You seldom hear through the media about grieving for a child and the impact their death has on all the various people involved.

It can destroy a marriage instantly, it can leave siblings hurt, confused and angry. Often siblings are too young to understand, they're angry that their family is not the same and even angrier that they don't recognize their parents. Losing their sibling is bad enough but so much more is lost for siblings that is never recognized. I could count on one hand the amount of times I've been asked how my boys were.

You might hear about the gory details surrounding a child's death in the media but that's about all. There should be so much more written about this topic, and additionally it should be talked about more openly than it is. I'm disappointed not just for me but for all the other grieving parents in society that this topic is met with so much fear and silence.

The bottom line is that people are uncomfortable with the situation and I really don't know why. My



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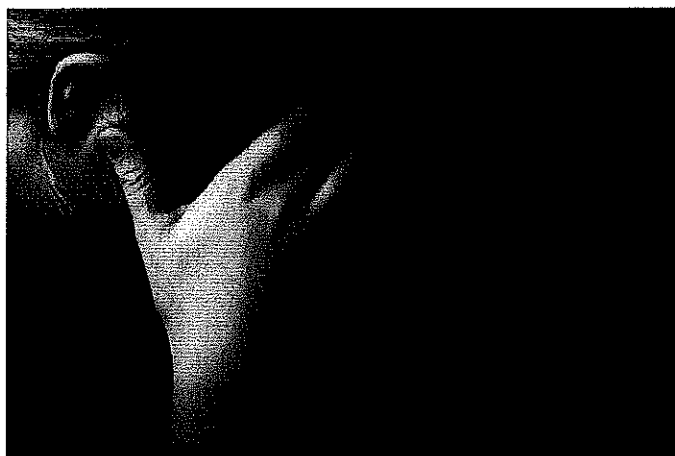
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feelings tell me it is such a horrific thing that most people don't want to know about it. Maybe they fear through knowing so much they might become obsessed with their own children dying. Parents worry enough about their children already. Do they really need the added worry about knowing how your child died?

Without question, my daughter Ella dying suddenly has been the worst thing that has happened in my 37 years here on Earth. I doubt that anything in my future is going to top it. Actually, just between us, I beg and plead with God on a daily basis that nothing ever does top that experience, but the truth is I just don't know.

I'm not a mind reader nor do I have a magic pair of glasses where I can see how the rest of my life will unfold. I just have to hope that nothing ever does, but I have a very real fear it will because it has actually already happened to me. I know without having to hold a psychology degree that having those fears is normal.



What I've endured, losing my little princess, has been so unimaginably horrific that I don't think I would survive something like it again.

What I have had to give emotionally to get through it has dwindled away all my mental strength – just like twenty cents pieces in a kid's piggy bank. I'm broke – not broken – I'm broke emotionally. I know all the energy I've needed over the last four years has not just been spent on my grief for Ella. It's been on trying to get my friends and family to understand what it's like to walk in my shoes. I'm angry about that. When I should have been grieving, I was defending myself.

I'm probably very close to being as angry about that as I am about her death. I wish I wasn't angry. Lord knows I don't need another emotion but I don't know how to not be angry, especially with some of the things that people have said and done to me. I talk and talk yet I'm often never actually heard.

I'm not sure if it's a lack of literature around or perhaps that people simply don't want to read it because it's so awful and they don't want to know someone they love and care about is experiencing so much agony. I personally know though, if I found out a family member or friend had been diagnosed with an illness or disease, or worse, their child, I would be on Google immediately finding out more about it and how I could best help. So why is it that this doesn't seem to apply with the death of a child?

Most people just think they know. I find this extremely frustrating. The death of your child is the worst thing that can happen to a person, yet most feel educated enough to advise, to criticize, to lend their words of wisdom when they don't know the first thing about it. Get over it? Why don't we see if you could get over it first!



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Most people wouldn't know that when I meet someone new I instantly become uncomfortable and filled with dread. I know at any moment when I engage in conversation the question is going to arise about my family and how many children I have. I would love not to have to tell them. Life would be a lot easier if I could take that path. However, I do have another child. Her name is Ella. She would now be four but she died when she was 19 days old. She isn't lost – I know exactly where she is, she's dead.

Ella is my third child and she deserves to be acknowledged just as much as my other children. I've lied before saying I have only three children, but the guilt that follows me around for days on end is just simply not worth it. I can actually hear Ella saying to me, "don't I matter anymore Mummy?" "Why were you too ashamed to talk about me?"

So personally for me, as much as I don't want to tell someone I don't know very well that my daughter is dead, the guilt of not acknowledging her is worse. I don't have three children, I have four and my daughter is not my only daughter – I have another as well. It's pot luck what their reaction is going to be. There's no telling what they're going to say. You just have to close your eyes, cover your broken heart and hope they don't plunge that knife further in.

If I could have my questions answered on why people give so much advice on a topic that they know so little about, it would really help me. What has surprised me so much since Ella's death is how little empathy there is in the world. Empathy to me is a no brainier. You just imagine you're in the other person's shoes, simple yes? Apparently not. Just think how you would like to be treated and if you wouldn't like it, don't do it. You never know what your life holds – one day it could be you wearing my shoes!

I hope this article about my personal thoughts and opinions helps at least one person understand to some degree what life is like for the bereaved parent ♥

I dedicate this article to my soul mate, Darren. I'm the luckiest girl in the world having you, my darling. I love you more and more every day, you're simply perfect and after fifteen years my heart still skips a beat when I see you. My friend Natalie Donnelly & her daughter Eryn. To put it simply: she is an angel and if the world was full of Natalies, it would be a better place. Also my bestie Liv thank you for letting me be and never smothering me with pointless words. Love you both xx



Samantha Hayward

Samantha Hayward is a stay at home mother married with four children. Tragically, 4 years ago her eldest daughter Ella died suddenly at 19 days to undiagnosed Viral Myocarditis.

*Retrieved on April 4, 2014, from <http://www.mamamia.com.au/parenting/ten-points-i-wish-every-person-knew-about-the-death-of-a-child/>; originally posted on 22 July 2013. Reprinted by permission of the author.*



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## LET US TOUCH: PALLIATION AND THE PHYSICAL EXAM AT THE TIME OF DYING

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*"Let us touch the dying, the poor, the lonely and the unwanted according to the graces we have received and let us not be ashamed or slow to do the humble work."*

-Mother Theresa

Prior to my rotation in the full-term nursery during medical school, I was never a "baby person." The appeal of holding those tiny little swaddled up bundles was a mystery to me, until sometime during that week, it happened. The little creatures won me over. Ever since, I haven't been able to resist holding a sleeping infant, whether mine or someone else's, and have even become pretty proud of my swaddling skills, which I show off to my pediatric residents any chance I get.

Baby M was no exception to being irresistible. Taking that four-and-a-half-pound baby, who had been lovingly wrapped in an Irish blanket, into my arms felt like the most natural thing in the world. She was a beautiful baby with perfect skin and small, delicate features. Her parents, like any, beamed with pride at their daughter. As I delicately unwrapped her and examined her, listening to her heart and her breath, palpating her pulses, assessing her fontanelles, I whispered and spoke to her as I would any other newborn baby. Her parents watched, mom from her bed and dad standing beside her, and I saw them look at one another, their pride replaced with love and sadness. I finished checking over Baby M, swaddled her up, and placed her back in the arms of her mother. Her parents looked at me with hope and fear, as I told them what I could hear and not hear, feel and not feel, see and not see on their daughter. The routine of this conversation brought a normalcy to the very abnormal situation: we all knew it would be a matter of hours, perhaps days, before this baby died. She had already surprised many doctors and nurses by simply surviving her birth.

When she was still not only alive, but relatively thriving, the following day, I again spent time checking over M. This time, rather than return her to her mother's arms, I asked them if I might hold her for a while myself. Partially to steal a few baby snuggles, but also to be able to keep a closer eye on her reactivity and her breathing for a longer period of time. I cradled her on my lap, her head resting perfectly in the palms of my hands, and swayed my knees back and forth just as I had with my own two boys when they were infants. It gave me time to observe her and get a sense of the changes that were coming her way, and her parents and I talked about making sure M was comfortable, and that they had all of the supports they needed, and we made a plan for their little family to go spend the rest of M's time at an inpatient hospice facility near their home.

What I didn't know at the time, but have been reminded of several times since, was what my actions of doing an exam and offering physical touch and comfort meant to Baby M's parents. To me, it was an appropriate way to assess their daughter, to offer them the best medical recommendations, as well as a way to sneak in a few moments of holding a sweet baby. For them, it was an act of normalization, a sign that their daughter, even with a terminal condition, still deserved full attention and consideration. It meant she wasn't just being "written off" because she carried an extra chromosome. It meant she mattered, and that she was an individual who should be seen and known as such, rather than only being judged based on her diagnosis. For a few minutes, there was comfort in the routine, a comfort I hadn't fully appreciated before that day.

The decision of whether to perform a physical exam, and to what extent it should be performed, on a patient who is in their final hours or days of life can be difficult. Families often request that we "leave him alone" or "not disturb her," and when those requests are made, it is certainly best to accommodate the



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family requests. Rarely is there a need to immediately perform the exam, and it is reasonable to wait until family or patient seem more comfortable with proceeding with an exam. At times we have our own concerns about causing more distress, pain, or discomfort, or about entering a room and invading what may be very important private time for the child with his family. Opting to examine a patient is like any aspect of palliative care: doing the right thing for the patient at the right time in a manner that is as comfortable as possible.

A physical exam, though, which so often can seem like something we do mostly just to fill out the right lines in the chart or check off boxes, can offer us, and our patients and families, so much more. For us, it can provide us information about the physiologic state of the body. As we observe the physical changes, we may have some objective data on which to base our attempts at prognostication. I've observed that as the heart begins to slow during apneic episodes it indicates a nearer proximity to death than the absence of this "reactive bradycardia" and I can tell families we have now more assuredly the timeframe of being within hours of death. I would not have gained this had I not gently placed my stethoscope on the chests of hundreds of dying patients. Examining the dying patient also affords us exposure to heart sounds and breath sounds that are rarely heard or are too unpronounced to be appreciated in the otherwise young and healthy patient. In hearing these, I've been able to tune my ear to the music of those murmurs and can now pick up on them when they are in their more subtle forms in my seemingly normal and thriving patients. In medicine, as we must commit ourselves to being lifelong learners, we cannot forget to continue honing our most basic of skill sets, and every opportunity our patients generously provide us to see and hear the hidden mysteries on and within their bodies should be respected and appreciated.

For older patients, the physical exam, when performed in a non-burdensome way, can provide them with a reassurance that we are not giving up on them or have written them off for dead. "The way I sound still matters" is the message on the stethoscope. "The way I move is important" may be what is felt when we ask to see examples of it. Patients, through what have likely been countless interactions with health care providers, have been conditioned to believe that a physical exam is a part of any encounter. In our pediatric patients, this is likely less the case, and for them, physical exams may have come to represent pain and unpleasantness. The sight of a stethoscope might induce fear or anxiety of what is to come next, and gradually working with them to let them know that *my* stethoscope is not a harbinger of pain, that *my* touch will only ever be gentle and comforting can be a way to designate oneself as an ally and a welcome provider.

Parents may also need time to gain trust in our approach to the physical exam, and again, over time, learn to see us in that light of a gentle ally. Other parents, like those of Baby M, may not yet have had the experience of watching their child struggle in pain with needle sticks and poking and prodding, and still see the physical exam as the most routine and normal thing that any provider does for their child. When the exam is not done, when their child is not touched, it signals that their child does not deserve the same kind of care as a "normal" child. It may signal a lack of concern or care, or even a fear, of the child. Also, we know that parents will follow examples of health care providers in how we physically handle a child. When we pick up their baby, hold their baby, coo at their baby, it sends an important message: your baby needs this, your baby deserves this, your baby can handle this. It may help allay their own fears or worries about holding their baby, and help them to create that important parent-baby bond. Many first-time parents handle their healthy newborns as if they are worried that anything could break the baby. This anxiety can be escalated when the baby has a life-threatening medical condition and parents may feel the baby is even more fragile, causing them increased anxiety about that physical contact. In our role as care providers, we have the ability to take away at least one component of worry in these parents' hearts.

It can also be beneficial to ask family to have some involvement in the physical exam. Just as pediatric providers know for outpatient exams, kids do best in the arms of their parents. The same is true for palliative and hospice patients. Parents can hold, or lay next to, their child to provide added comfort. When a family member says, "Oh, let me get out of your way," I encourage them to stay just as they are and explain that I can work around them as long as they are comfortable with that. If I do need to reposition the child, or move blankets or stuffed animals, I ask if they mind helping me do so. I also ask them what changes they have noticed, usually before I comment on the changes I have noticed. If I see



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mottling developing, rather than announcing this to the parents, I let them tell me. As I am looking over a child's feet and legs, I might ask, "Have you seen anything different about her body today?" They may reply, "We noticed her feet are colder today, and kind of purple." Requesting and validating the parents' observations reinforces that we see them as the most essential part of the care team. It also opens the conversation regarding how those findings relate to prognosis. In doing this, it can create a space for their worries or questions to be explored so we can continue meeting their emotional needs while providing them with medical information about their child's condition. Especially for parents who have read books or pamphlets or websites about the dying process, and who know that certain changes indicate that movement toward the time of death, letting them voice those findings, and then following up with, "Sometimes people get worried when they see those color changes. Does it worry you?" This allows them to say, "I read that this happens right before someone dies." And perhaps to follow up with, "Do you think she is close to dying?" It lets us gauge their readiness for information and need for more information or more support so that we can meet them where they are.

As in all aspects of palliative and hospice care, making decisions about what interventions we conduct is done by weighing the benefits and burdens of those interventions. At times, conducting even a brief physical exam can feel burdensome without any benefit other than to complete our documentation. Until I saw Baby M, most of the time my physical exams were done more from a compulsion of "I have to do it, and I feel bad about doing it." After meeting Baby M and her parents, though, my perspective changed and I was able to have my eyes open to the other benefits of the physical exam that go beyond the physical and into the whole-person, family-centered care we all strive to achieve.

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## LAST HOURS: THE MOST TENDER OF JOURNEYS

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For team members dedicated to Pediatric Hospice, the last hours can be the most delicate, tender, honorable time. The hospice team is making sure that families understand what is happening, being supportive, guiding, and educating regarding decisions about the "time of death." Many families that have a dying child, have never been to a funeral, much less had to make "arrangements" for their own child. Families hold out hope in their hearts for a "miracle" to the very end of the journey, even though they are aware in their minds that death is a reality.

Difficult conversations with families about death are not easy, even for hospice professionals. Questions must be asked about the practical details of death, such as "What funeral home are you using? What clothes do you want your child dressed in? Is there a special toy or blanket you want to send with your child?" It has been my experience that most families do not have the energy to discuss these matters before their child dies, while some families have made some decisions privately and decline to discuss the matter with the team. Their hearts are full and broken as they watch their precious child take final breaths and they cannot put into words their choices for their child. The hospice professionals may be present at the time of death, or they may arrive after the child has died. I have found that the best practice is to gently discuss a few details once the child is imminently dying:

- Inform families about the process of "pronouncement" according to organizational policy. This can be done in a gentle, concise manner.
- I would always let the parents know that whatever decisions they make will be the right ones. Most families have just "wrapped their head" around the fact that their child is going to die, and they cannot "go there" to think about the very end of the journey, death. There are several options listed below for team members to think about, discuss, and offer to families at the appropriate time. The "appropriate time" is different for each family, so collaboration within the IDT is a "best practice," as one team member may have a closer relationship with the family than another.
- Explain to families that they could call right away, if staff is not present, or they could take some time before calling the hospice professionals. This is a very tender time for parents and families. They may want their immediate family present, or they may want this to be "their time" with their child.
- Families may want a minister or Chaplain to be present, even if they have refused services previously. If there are siblings or other children in the home, be sure they have their questions answered, after collaboration with the family.
- There may be cultural practices surrounding the time of death. Make sure these are discussed prior to the time of death, or at least ask families about their cultural or religious practices. One of our families wanted the child to stay in the home overnight, and then have the body prepared and returned to the home until the funeral two days later. It was a beautiful time for the family and the other children in the home participated in their rituals.
- Give families the choice in post mortem care. Some families wish to provide post mortem care themselves, especially if the child is older or a teenager. I had a grandmother tell me recently, "he (the patient) would not have wanted you to clean him," so she provided the care. Some families wish to assist, or bathe their child one last time. Respect for this ritual, if they desire it, is a most tender moment. Some families are too distraught to participate, and this is okay, too.
- Families have the choice to take the child to the funeral home, or have the funeral home come to their home. Some parents cannot bear to have someone come into their home and "take" their child. Please be sure to follow policies of your organization, or try to institute new ones specific for pediatric patients.



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- The family has the choice of what clothes to dress the child in for the trip to the funeral home. They may want the child dressed in a special t-shirt, or they may desire for the child to wear the clothes they were in when they died. They can also send a stuffed animal, photo, or any other memorabilia.
- The family has the choice to carry the child to the funeral home's vehicle, or have the funeral home come inside. If the funeral home comes inside the house, I always gave the family a private moment before the body is carried out because this will be the last time they see their child in their home. I always speak to the funeral home prior to coming to get the child's body and ask them to not use a "body bag" and not to cover the child's face. Several parents have asked the funeral home staff if they will "take good care" of their child. The hospice team can play an important part in providing support by assuring the family, if the funeral home staff does not mention this.

After the child's body has left the home, it is appropriate for hospice staff to offer condolences, provide support to the family, and begin closure for the hospice relationship. It is the start of the shocking grief journey for parents, and supportive touch, a caring presence, or just caring silence will be the last impression with families. The family will never see their child again in their loving care, and the finality of their child's most tender journey becomes a reality. One of the most poignant memories I have is with a family that "tolerated" me as the hospice nurse. I had pushed too hard in a conversation about the changes in their child's condition, and they were not ready to hear information about their child's decline. When I came to pronounce the patient, there were many people in the home, including their minister. After the body was removed, and I gave the mother a hug, she said to me, "Thank you for not leaving us." I was asked to hold hands with the group, as the minister gave a prayer. A year later, the mother sent me a card, expressing her appreciation for the care of her child. Parents never forget that final moment.

If "On Call" or "After Hours" staff pronounce the patient, if possible, call and speak to that staff member before the primary team members reach out to the family to offer their own condolences. It helps if you know some details to offer support, as families may or may not want to discuss the events with the primary team member. Attend the celebration, funeral or service if at all possible. Families remember years later the "team" that attended a time to honor their child.

Just as each child is an individual, so is their death. Learn from each one and build upon knowledge to serve families at their greatest hour of need.

Children deserve no less.



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## WHEN THE TIME COMES: LITTLE THINGS REALLY MATTER

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Parents prepare in great detail for the time surrounding the birth of a child. In the United States there are many unique ways in which this event can be preserved, choreographed, and shared with friends and family members. When the sorrowful time arrives at the end of a child's life, there are similar ways to make the experience personalized, poignant, and deeply dignified. Great consideration must be given to these final hours together for the lasting impact they may have upon the family.

### Suggestions to introduce to a family

Do they plan to have any siblings present as this time approaches or not? Who will explain this? It would be best if the other children to be present have a reasonable understanding of what they should expect—with all senses. What will they see and hear? What will the child feel like? Allowing the sibling to make a choice is often neglected and later can create additional grief issues of not being able to say goodbye or witness the reality of their brother or sister's death. Every family has their own unique beliefs on this but may not be aware of the benefit and closeness that can come from being together around the dying child (with preparation) rather than sending the sibling away, not including them at all, and missing the intimacy and intense love that comes from sharing this time as a family unit.

Explain touch regarding temperature, responsiveness. Are there sounds to be prepared for? Is there technology that can be minimized to soften the surroundings and not have them become the focal point for loved ones? Try to remove any DME or supplies not needed at this time in the child's care to simplify and streamline the environment. This allows for family members to be as near as possible and as unencumbered with hospital-like setting reminders as possible. Some families plan as if it were a birthing plan, to have chosen music that is comforting and familiar to their child playing. They may invite close friends or loved ones to be in attendance as the time draws nearer.

Eight-year-old Matthew had created an invitation list for who should be at his side as he was dying. He created Valentines for each loved one and had purchased a small cross for his siblings prior to this time to be given to them for comfort in his eventual absence. "Guests" were of all ages, but an intimate group surrounding his frail body as he lay on his parents' lap on the couch in the "heart of the home," the place where he was lying—on the couch with family cocooned around him.

We can ask parents if they have thought about a mortuary at this time, if it has come up naturally or arranged previously in order to give funeral service providers advance notice that they will be picking up a child at the residence. This may insure a smoother transition when the time comes to have the child's body leave the home. This decision can be handled with great tenderness. The most reverent of processions can occur when a parent (often a role the father can assume) lovingly carries the precious child from the home to the waiting van or other vehicle. Mortuary attendants must be notified prior to arrival about the age of the child to insure they pay close attention to the unusual nature of the situation and allow for time and intimacy. Typically, the scenario can be described to parents so they can choose who carries the child, thus creating a more gentle departure than being "taken away" from the home. It creates a small sense of control in an impossibly difficult moment, *surrendering* the body to the hands of the funeral home attendees rather than *removed* or taken from their home. The subtle difference can make a big impact.

Requesting that the face not be covered in front of the family is another option, as is not having a baby strapped in a car seat but held in the car. Some counties may allow for parents to transport the child themselves, but care must be given to insure they are safe and clear minded enough to drive.



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Siblings may wish to send something small to accompany the child: a small token to symbolize their inseparable relationship and love for the deceased. A note, flower, picture drawn, or letter written for burial with the child by loved ones may be comforting and a release of what words alone cannot relieve.

Hospice staff can help inform parents of "what happens next" and the decisions that may need to be made at the time of death. There are many families who choose *not* to have the hospice/ home health team present at this time. Partly because they want it to be just family, but also because the team may indeed have prepared the parents sufficiently to be able to stand on their own, knowing help is available if needed but confident they now know what to do at this most intimate of experiences. As mentioned at the beginning, not unlike the delivery and birth of a baby, it is not random who is there in attendance at the time of death.

Parents will need to be prepared for what the actual process will look like, sound like, and how to help keep the child optimally comfortable. Providing written guidelines of possible things to observe and related comfort measures can help provide a sense of increased confidence and competence for the parents in this final care giving role. Knowing how to comfort and better understand what is happening will diminish anxiety and feelings of fear and helplessness. Having medications on hand (Emergency kit) prior to the end of life to address symptoms unique to the child is highly recommended. There may be little warning that the dying process is rapidly approaching and anticipation of potential problems and symptoms is key to achieving a peaceful dying process. Parents also need to know who to call when death occurs and when that may be recommended, what to expect from the body when death occurs, and how much time they may desire with their child before calling the team. (Note: this time and requirements at time of death may greatly vary depending on where the child resides. Be sure the team is informed and prepares accordingly!) Removing as many medical devices or equipment no longer needed from the child's care setting can be a relief to restore a more "natural" setting at home and allow the focus to be more on the communication and tactile connectivity to the child rather than focus on pumps, tubing, and machine indicators.

### **Rituals at time of death**

Some families may wish for a clergy or faith community representative to be present or called shortly after the death occurs for prayers or specific rituals that must/ wish to be provided. This also requires prior knowledge to best advocate for the family's wishes, needs, and desired outcomes. Bathing their child once more, gently redressing, holding, rocking, and laying down with the child are all possible tender moments they may wish to share and may not know if this is "normal." Give them suggestions that have helped other parents and allow them to choose or decline any or all options given. Privacy may be hard to find if many relatives are present. The hospice team can also gently suggest to family members that they offer a time for the parents to be all alone with their child, as they were when he or she was born.

### **Keepsakes**

There is much to be said about creating keepsakes for families, but the following will focus on the time surrounding the process near the moment of death. If attempts have not been made previously to obtain any tangible keepsakes of the child before, now is the time.

- The simplest is to make handprints of the child and/or of the child's feet depending on age. Adding the handprints of a sibling, parent, or close friend can be done at a later time. Allow enough time or supplies to make several, as they will not be possible later. Grandparents and friends are often left out of this process and may be truly grateful for the gift. Also, adding multiple handprints to a larger page of pasteboard is a lovely way to create a "family portrait" of hands, in a horizontal line, in a circle like a wreath shape, or overlapping in a collage design of hands. Framed, these can be a focal point of comfort and presence for years to come.
- Parents may be given the option of saving a clothing item in a zip-locked bag, the scent being a potent way to connect to memories later. Clothing or pillowcases make good samples.
- A small swatch of hair may be saved, collected from the very back of the head or from the nape of neck. A small ribbon can be tied around the hair and placed in a small jewelry pouch for a keepsake.



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- Encourage parents to avoid a hasty removal of belongings after the child's death. There may be items that can be given as gifts to friends and family and treasured or made into comfort bears (to learn more about Cuddle Bears available through Elizabeth Hospice go to <http://cccforhope.org/grief/> and click on "Cuddle Bears")
- Friends may be interested in purchasing a COMFORT CUB® especially when the child was an infant or for a sibling. These weighted teddy bears have been found to be very effective in relieving the ache of empty arms and broken hearts for parents or siblings. (They are also very adaptive to give to children who lose a parent; see [www.thecomfortcub.com](http://www.thecomfortcub.com).) Some hospices get them underwritten by grants or from donors to distribute to families.
- Tender photos of the child, with family members, perhaps in black and white or using the local volunteer photographers from "Now I Lay Me Down to Sleep," may be planned in advance. Taking photos of only hands is another alternative if the family is opposed to facial photos or after the child has passed or is dying.
- Suggestions are offered and each family makes best choices for themselves, but gently helping them understand opportunities are fleeting and once gone, cannot be reconsidered. They can save or set aside the keepsakes and not reach out for them for long time, or they may be a comfort and desired to be immediately at hand.
- A Memory Box can be an inexpensive gift to family for them to collect a few keepsake items, small belongings, cards and letters, memorial service items, etc. This can be set aside or remain close for comfort and reflection. One for any siblings would be a good suggestion for them to return to when needed for reminders, additions of letters and cards, etc. Photo storage boxes, available at craft stores, are inexpensive and sturdy. Photographs or handprints can be placed on the lid of the box or familiar symbols, or pictures that reflect the child's interests.

### Transitions

As at other times in the child's illness, there are transitions that occur at the end of life. It is typically best for the family if the child remains in the present location when death is truly imminent within hours to a day or two unless this is the goal and desire of the family. Then it is highly advisable to advocate and take action for this to be fulfilled. Prior planning with options for hospices that can accommodate the care at end of life for babies and children is essential. Successful transitions require a commitment to see the other provider's needs, issues, and challenges, and attempt to work together to create the desired/best outcome for the family.

The next transition comes when the role of the team caring for the family ends and they will be transitioning to those who will be providing bereavement support to them if they have not already connected or been introduced. It is wise to "manage up" and advocate the use and benefits of seeking the expertise of those who provide bereavement support to be a safety net for the time that follows and help guide them through what to expect, how to address the grief of siblings and grandparents, and re-entry to work force or life in general. A clear plan should be communicated to parents so they do not feel any unexpected severance of support from those they knew well. Nor should they feel unimportant when the time comes to end the relationship from one role to the care and support of the next team of bereavement professionals.

Last, the need for staff to make time to have their own rituals, reflection, and attention to their personal and professional grief and emotions is just a core function of the provision of hospice and palliative care services to children. Those who care for these children and families need and deserve the support for their own needs and issues in order

To be fully present to the next family, as well as to balance the loss with the insights of the many gifts that come from this work, to foster openness and ability to show compassion for themselves and each other. The circular nature of these beginnings and endings can be gently handled and lovingly carried out. If so, it will provide a profound sense of dignity, respect, and honor to the life they shared and the love and grief that now converge powerfully.



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## WHEN THE TIME COMES: HOW TO HELP WHEN A CHILD DIES IN THE HOME

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*When the call comes in that a baby or child has died in the home, it may be a challenge and even a bit overwhelming to think of what you will do to be of help and comfort to the grieving family. Below are some guidelines that may help you approach the situation a bit more prepared and thus more capable of making the process a little less painful for the parents and family.*

- ♥ Most parents may not directly ask for a home visit, but usually appreciate and often benefit from a visit at the time of the child's death. Just having someone there to help orchestrate the process when they may be feeling overwhelmed and paralyzed by their grief will be helpful. If they refuse, then there are still things to do that will be helpful for them over the phone. It is most likely that they will not need the nurse or other team members to stay for the entire time until the child is taken from the home.
- ♥ The family should be allowed to have as much time as they need with their baby or child before the mortuary comes to take their child's body. It may seem unusual to you that they would want to keep the body for many hours, but it is a very final step to have their child taken from the home. The mortuary can be notified with the appropriate information required at time of death, but informed that the family will contact them directly when they are ready.
- ♥ Try to suggest to the parents/caregivers to take some private time alone with their child, without all the family around. This is a very intimate and personal time for them and may help to facilitate the process of "letting go" and saying goodbye. Others in the family may also wish to have some private time with the child to say a personal goodbye.
- ♥ Encourage the parents/adults present to give any other children in the home or family the choice to go in and say goodbye. Children of most any age are able to decide for themselves if they want to see the child who has died. By just offering the child the choice, it has given the child a sense of control during an unfamiliar and unsettling experience. They will remember that someone thought enough of them and their relationship with the person who died, to give them the chance to say goodbye. The child should be prepared in simple language for what the child will look and feel like, that they will not move, etc. It's a good idea to remove any tubing from infusions, oxygen tubing, catheters, etc., to normalize the appearance at the bedside as much as possible. Someone he/she feels safe with should accompany the child. If the family plans on cremation, this may be the last opportunity for them to see their sibling, thus there may not be a second chance if not now. The child may wish to go in for just a "peek" or they may be curious and want to stay around. Whatever length of time the child chooses to stay is okay and should be up to them.
- ♥ Allow parents to have the time they need to perform any private rituals or activities, which may include bathing the little one, redressing the child into something special, rocking, a blessing or time for prayer around the bedside. They may wish to have their priest, minister or chaplain come to the home.
- ♥ Offer the parents the suggestion of saving a lock of hair if they have not already done so. They may not feel comfortable doing this themselves and may wish for the staff person to do this. The nape of the neck or the back of the head is the best places to obtain a swatch of hair. It can be tied with a piece of yarn, thread or ribbon. The hair can be placed in an envelope and sealed. Explain that they



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may not wish to look at it or have it now, but that someday they may be glad they had this small remembrance, something tangible that connects them to their loved one, their precious child. A comfortable way to present these suggestions to the family is to say that these are some ideas and suggestions that other parents/families have found to be comforting. They may choose to do all or none of these activities, the point is to make it meaningful for themselves as a family.

- ♥ There are instances when the family may want to take pictures of the child after death. They may wish to keep them for relatives who live away or for cultural reasons. A family may ask for your assistance to do so, or they may obtain them at the mortuary.
  - ♥ If the primary team has not already done so, it may be important to offer the suggestion of taking handprints and/or footprints of the infant or child. Someone could go out to purchase an inkpad, poster paints or tempera paints if nothing is available in the home to improvise with. These supplies are available to the staff in the resource area. Keep a soapy washcloth or alcohol handy to quickly remove the coloring from the extremity. It's best to try to do the prints as soon as possible before any stiffening of the body sets in. Again, if there are other children in the home it will be significant to obtain at least one print for the sibling to have for later on. Other family members can add their handprints also, creating a "family portrait" of hands.
  - ♥ When contacting the mortuary, emphasize that it was a child that died so that they will be sensitive to the situation they will face. When they arrive at the home, the family may need to say a last goodbye. Rather than have the child taken from the home by the mortuary attendants, we have found that is much less painful if one of the adults/parents carries the child out to the vehicle and surrenders over their child to the arms of the attendants. Parents have told us it felt less traumatic than if they stood back and the baby was taken out by "strangers." Occasionally this process becomes an informal processional to accompany the child out of the home for the last time.
  - ♥ If at all possible when the child is ready to be carried out of the home, ask the attendants to keep the child's face and head uncovered and not enclosed completely. The use of the body bag is very distressing and offensive to most parents/family. Perhaps the child can be wrapped in special blanket and/or a sheet. Sometimes the driver is willing to take the little one partially covered like this until away from the home, then secure the child's body after leaving the area. Siblings can add a special keepsake to accompany the child's body i.e. a note, flower, drawing, or stuffed toy.
  - ♥ Remind the family of the bereavement resources available to them, that the primary team will be following up also. Request that arrangements for funeral/memorial service be communicated to Hospice team unless it is private, family only. If visit made after hours, notify primary team of how the family is coping and report on events surrounding the child's death. The primary team can follow-up with their sick child's or sibling's school with permission from the parents.
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## GUIDELINES FOR CARE AND CARING AT THE END OF A CHILD'S LIFE

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It is difficult to accept that the death of a child is possible, let alone likely. However, discussing preferences for end-of-life care in advance with the child (if appropriate) and family will support goals of care and minimize the burden on the family when anticipated death is near. The items in these guidelines are prompts to encourage discussion and planning. Some possible scripting is included to get you started. In general there should be a plan, regular review/update of the plan, and review to ensure compliance with the plan.

Imagine that you are a health care provider caring for Maria, a 13 year old for whom cancer treatment has failed. Her oncologist expects that she will die in the next days or weeks. How can you best care for Maria, her family, and yourself? How do you bring up difficult topics?

### 1. Goals of care

- Is there clarity about the child's condition, prognosis, and goals of care? Communicating with children should be honest and developmentally appropriate.
- Are the goals of care documented? A written advance care plan documents preferences, facilitates compliance and consistency of care, and empowers the child/family. An anticipated death should be documented in the medical record as well as a "do not resuscitate" order, if that is the child/family's preference.
- Are there changes in the goals of care? *Maria, you have tolerated some mild pain because you wished to be alert enough to go to school. Is this still what you want or should we try to maximize your pain control even if the medicine results in some sleepiness?*
- Are the goals of care disseminated to all current and potential future care providers? *When we finish our discussion today, I will update the advance care plan, and give you and Maria's care providers a copy.*
- Are the advance care plan and orders consistent with the goals of care?
- Is the treatment by all care providers consistent with the child/parent preferences and goals?

- 2. Preferred site of care:** The options may be home, hospital, or hospice. Most children/families choose home, with some choosing a familiar hospital setting. The room should be calm, not brightly lit, cool, and contain familiar belongings and pictures. Many families also choose some aromatherapy. A bulletin board is a good place to put memory pictures, photos, and notes from friends and family. *In the past, you have strongly preferred to have Maria's care provided at home. Is this still your hope? We will be available to support Maria, you, and your children to ensure that she can be cared for at home. However, some families like to have a back-up emergency plan in case Maria's symptoms become unmanageable or you feel that you need more help than can be given at home. Do you wish to develop a plan for transport to the children's hospital just in case?*

### 3. Assessment and management of physical pain and other symptoms

- Review likely signs that death is imminent. *With Maria's type of cancer, the following are possible signs that death is near: \_\_\_\_\_.*
- Anticipate and plan for management of likely symptoms. There should be 24/7/365 access to a provider who can assess and manage symptoms. There should be a plan for who will prescribe medication and where medications will be dispensed. Many hospice programs have symptom management protocols. In some states, the hospice or visiting health care nurse has a medication kit. *Because we anticipate that Maria might experience new or increased*



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- c. \_\_\_\_\_, we recommend that you have \_\_\_\_\_ medication in the house. Because this is a controlled substance and cannot be phoned in, I'll give you a written prescription. Please call us if you feel that you need to start/increase this medication. Is there a 24 hours pharmacy available to you if you need to get other medications on short notice? If Maria experiences symptoms that cause her distress, please call us at \_\_\_\_\_.
- d. Discontinue any medications/treatments that are no longer beneficial. As Dr. Johnson has reviewed with you, chemotherapy is no longer helping Maria, and, in fact, is making her feel worse. As our goal is to help Maria feel as good as possible, Dr. Johnson has recommended stopping the chemotherapy and focus on optimizing Maria's comfort and quality of life.
- e. Plan for nutrition/hydration. In most children near death, intake is voluntarily decreased. Artificial nutrition and hydration may, in fact, increase respiratory distress. As Maria nears death, she will likely eat and drink less. This is a sign of the dying process. Giving fluids artificially may make her breathe harder and cause her distress.

**4. Address emotional, psychosocial support.** Urge parents to have a plan for self-care and care for the family. There should be a plan for which health care providers and other support people that the parents wish to be present near the time of death. It is important not to ignore siblings, grandparents, school friends, and the broader community. It may be helpful to have a designated adult to help provide support to the siblings of a dying child. Find out what organizational support resources are available in your community.

**5. Address spiritual support.** Religion, spirituality, and life philosophy influence coping, finding meaning, and decision making at end of life. Health care providers should be aware of and sensitive to death and dying customs in world religions and cultures. For the child, be prepared to address their concerns about dying, life after death, loneliness, loss of the future, guilt, and struggles to find meaning. Ask the family what is important to them and how they find support. A trusted faith provider, friends, nature, or any experience that helps them to find meaning may provide support. Hospices and most palliative care programs have staff chaplains who will provide spiritual support. Rituals provide an important role.

**6. Address financial and insurance issues.** Assess the family's needs. How is the family going to manage lost time from work? Is family leave available? Does insurance cover respite care? Part of the Affordable Care Act ensures coverage for "concurrent" care but not all states have funded this. The hospice/palliative care program's social worker will likely be of help.

**7. Plan for memories/mementoes.** Help the child/family develop a plan for collecting memories. *Maria, have you thought about how you would like to be remembered? What is most important that people remember about you?* Here are some suggestions:

**8. Distribution of belongings**

- a. Celebration of early birthday, holidays, graduations
- b. Hand/foot casts
- c. Handprints/footprints
- d. Lock of hair
- e. Keepsake jewelry or ribbon
- f. Memory box
- g. Planting a tree or garden of remembrance
- h. Have the child write a story or paint a picture
- i. Book of memories.
- j. Photographs. *Have you thought about having photos taken of Maria with her siblings? Now I Lay Me Down to Sleep is an organization of volunteer photographers who will provide beautiful photographs.*
- k. Plan for responses to others who wish to honor the child. *If you would like to honor Maria, consider sending a donation to \_\_\_\_\_, sending flowers to the church/funeral home, contributing to a scholarship for \_\_\_\_\_.*



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## 9. Plan for after death care

- a. Who to call to be available if desired? There should be 24/7/365 access, if desired, to a health care provider to answer questions, provide support, and to be present. Names, contact information and indications for calling should be documented.
- b. Support rituals around the time of death. Ask what religious/ethnic/cultural rituals will help the family make meaning of this event. *What is important to you and your family after a child has died?* Some parents appreciate some suggestions or "guided participation." *Some parents like to have family members and other loved ones place their hands on their child.*
- c. Address care of the body
  - i. Do the parents wish to hold or lie next to the child for a while after death? Do they wish to bathe and dress their child? If the child is to remain at home for more than 4 to 6 hours, have a plan in place to cool the room and inform the family of expected changes in their child's body.
  - ii. Who will carry the body out of the house? Have a plan in advance. Siblings and parents may be distressed if the body is carried out of the house to the hearse by the funeral home staff or if the face is covered.
  - iii. Who will transport the body? Funeral directors can be of great help. In some states, parents can transport the body to the funeral home or to the hospital for autopsy.
  - iv. Will there be burial or cremation?
  - v. Is organ/tissue donation an option? Always check with your regional organ procurement organization when death is anticipated. Determine if organ and/or tissue donation is an option and determine the proper procedures. If organ donation is an option, site of death may need to be in the hospital so that organs can be rapidly retrieved. All families should be informed of their options regarding donation and make choices based on their values. *I have checked with the regional organ donation organization. Because of Maria's cancer, she is not eligible to donate her organs. She may be eligible to donate tissue for research. Is that something that you wish for more information about?*
  - vi. Do the parents want an autopsy? Even with modern technology, an autopsy can be useful to gather additional information about diagnosis, genetics and risks of the condition in the family, and contributing factors to the death. In some cases a limited autopsy or obtaining tissue for genetic studies is useful. Some families find this information helpful in grieving.
- d. Who will declare death? Rules may vary between states. For instance, a hospice nurse but not a visiting home health nurse can declare death in Minnesota. Be informed of the rules in your state in advance of the death. Having the police come to the house to declare death is rarely a good option.
- e. Who will communicate with the medical examiner/coroner/child death review panel? Determine in advance who will report the death to the appropriate agency.
- f. Plan for communication with health care providers and others. Ensure that the primary care providers, hospital care providers, school, other care providers, and those requested by the family are aware of the death.
- g. Prepare for funeral/memorial service/celebration of the child's life. You can help the child/family plan in advance for the coffin/urn, the child's clothing, details of music/song/readings, care of the siblings, flowers, donations, release of balloons, lighting candles, and a gathering after the service. After death, the family can work with the funeral director or celebrant to arrange for the date/time/venue of the funeral or memorial service. Prepare for a way to inform others of the service, your wishes, and memorials.
- h. Provide bereavement support. Support the family in accepting the reality of the loss of their child, experiencing the pain of grief, adjusting to the new reality without their child, and move on with life while remembering their child. Explain some of the emotional and physical symptoms that they may experience. Lay support groups such as Compassionate Friends, SHARE, and RTS (Resolve through Sharing) are frequently helpful. Be informed of available bereavement resources in your community. Timing of self-referral is dependent on the family. Funeral directors are increasingly experienced in supporting bereaved parents and siblings.



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Hospice programs and most palliative care programs include regular bereavement support. A post-death visit with the main physician is frequently beneficial. *Have you thought about whom you consider your family's best support? Have you thought about how to answer when friends offer to help? Perhaps you could make a list with items such as providing meals, grocery shopping, house cleaning etc. It is often helpful to have an adult who can support Maria's siblings during this time that will be very stressful to you. There is an active RTS group in town. Many families find great solace in talking to other families who have gone through the death of a child. I will leave the information with you to look at when you are ready.*

*"Parents don't need consolation - what could possibly console? Parents need the tools to walk through the fire without being consumed by it."*

- Emily Rapp, *The Still Point of the Turning World*

- 10. Care for the health care providers.** It is important that health care providers have opportunities for reflection, debriefing, and support. Hospice and palliative care programs should have such support built into their program. Set a date, time, and location for the debriefing.

### Resources

A Guide to End of Life Care. Together for Short Lives.

[http://www.togetherforshortlives.org.uk/assets/0000/1855/TfSL\\_A\\_Guide\\_to\\_End\\_of\\_Life\\_Care\\_5\\_FINAL\\_VERSION.pdf](http://www.togetherforshortlives.org.uk/assets/0000/1855/TfSL_A_Guide_to_End_of_Life_Care_5_FINAL_VERSION.pdf)

End of Life Planning Prompt Sheets. Together for Short Lives.

[http://www.togetherforshortlives.org.uk/assets/0000/1857/TfSL\\_EoL\\_Planning\\_Series\\_Prompt\\_Sheets\\_4.pdf](http://www.togetherforshortlives.org.uk/assets/0000/1857/TfSL_EoL_Planning_Series_Prompt_Sheets_4.pdf)

Being with your child at the end of life's journey: Knowing when death is near and how to ease the way with love. British Columbia Children's Hospital and Canuck Place Children's Hospice. February, 2004. Very helpful information for families including review of signs of impending death, preparing for and determining death, and the post death period.

<http://www.cw.bc.ca/library/pdf/pamphlets/Being%20with%20your%20child%20BCCH%201006.pdf>

Honouring the spirit and caring for your child after death. British Columbia Children's Hospital and Canuck Place Children's Hospice. February 2004.

<http://www.cw.bc.ca/library/pdf/pamphlets/Honouring%20the%20Spirit%20and%20Caring%20for%20your%20Child%20After%20Death.pdf>

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Dussel V, et.al. Looking Beyond Where Children Die: Determinants and Effects of Planning a Child's Location of Death. *Journal of Pain and Symptom Management*. 2009;37:33-43

Feinstein JA, Ernst LM, Ganesh J, Feudtner, C. What New Information Pediatric Autopsies Can Provide: A Retrospective Evaluation of 100 Consecutive Autopsies Using Family-Centered Criteria. *Arch Pediatr Adolesc Med*. 2007;161(12):1190-1196

Ferris FD, von Gunten CF, Emanuel LL. Competency in End-of-Life Care: Last Hours of Life. *J Palliat Med* 2003; 6: 605-613.

Foster TL, Bell CJ, Gilmer MJ. Symptom Management of Spiritual Suffering in Pediatric Palliative Care. *Journal of Hospice & Palliative Nursing*/ 2012;14:109-115. Nice discussion of child's spiritual concerns surrounding death.



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Hexem KR, et.al. How Parents of Children Receiving Pediatric Palliative Care Use Religion, Spirituality, or Life Philosophy in Tough Times. *J Palliat Med* 2011;14:39-44

Kobler K, Limbo R, Kavanaugh K. Meaningful Moments: The use of ritual in Perinatal and Pediatric Death. *MCN* 2007;32:288-295. Nice review of meaning of rituals and examples of rituals for groups.

Knapp CA, et.al. Family Support in Pediatric Palliative Care: How Are Families Impacted by their Children's Illnesses? *J Palliat Med*. 2010;13:423-425.

Knapp C, et.al. Spirituality of Parents of Children in Palliative Care. *J Palliat Med*. 2011;14: 437-443

Sullivan J, Monagle P. Bereaved Parents' Perceptions of the Autopsy Examination of Their Child. *Pediatrics* 2011;127:e1013-e1020

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## CHECKLIST FOR CARE AND CARING AT THE END OF A CHILD'S LIFE

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### Goals of care

- ☐ Clarify condition, diagnosis, prognosis
- ☐ Document goals of care/advance care plan
- ☐ Document changes in goals
- ☐ Disseminate goals/advance care plan to all providers
- ☐ Ensure orders are consistent with goals
- ☐ Ensure treatments are consistent with goals

### Preferred site of care

- ☐ Document preferred site of care and death

### Assessment and management of physical pain and other symptoms

- ☐ Review signs of imminent death
- ☐ Plan for management of likely symptoms
- ☐ Discontinue non-beneficial medications/treatments
- ☐ Develop plan for nutrition/hydration

### Address emotional, psychosocial support

- ☐ Facilitate family's plan for self-care and support
- ☐ Plan for adult to care for siblings as appropriate
- ☐ Clarify community support resources

### Address spiritual support

- ☐ Address child's spiritual concerns
- ☐ Determine family's source of spiritual support
- ☐ Support family's rituals
- ☐ Involve the hospice/palliative care program's chaplain as indicated

### Address financial and insurance needs

- ☐ Assess family financial and insurance needs and develop a plan
- ☐ Plan for family leave, respite care, "concurrent" care as indicated
- ☐ Involve a social service provider as indicated

### Plan for memory making/mementoes, some considerations:

- ☐ Help child determine distribution of belongings
- ☐ Determine how child wants to be remembered
- ☐ Plan early celebrations
- ☐ Make hand/foot casts and/or prints
- ☐ Cut lock of hair
- ☐ Obtain keepsake jewelry or ribbon
- ☐ Help make memory box
- ☐ Suggest remembrance tree, plant or garden
- ☐ Suggest child artwork or story
- ☐ Recommend book of memories
- ☐ Encourage photographs



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**Plan for after death care**

- ☐ Plan for which care providers to call
- ☐ Document contact information and indications for contacting
- ☐ Query about rituals
- ☐ Support rituals
- ☐ Address care of the body
  - ☐ Offer holding; lying next to the child
  - ☐ Offer opportunity to bathe and dress the child
  - ☐ Plan for room cooling as indicated
  - ☐ Plan for carrying body out of the house
  - ☐ Plan for transport of the body
  - ☐ Decide on burial vs. cremation
  - ☐ Determine if organ/donation is an option and chosen
  - ☐ Determine if autopsy chosen
- ☐ Plan for declaring death
- ☐ Plan for communication with medical examiner/coroner/child death review panel
- ☐ Plan for communicating with health care providers, school, others that parents choose
- ☐ Prepare for funeral/memorial service/celebration of the child's life
- ☐ Provide bereavement support
  - ☐ Support family as they grieve
  - ☐ Explain some of the physical and emotional aspects of grief
  - ☐ Refer to bereavement support groups
  - ☐ Provide regular post-death contact with the family
  - ☐ Schedule a post-death visit with the main physician

**Care for the health care providers**

- ☐ Schedule a post-death debriefing for the care providers
  - ☐ Provide opportunities for reflection and support of oneself and others
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