

Pediatric Starter Kit:

Having the Conversation with Your Seriously Ill Child

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

We developed the original Conversation Starter Kit as a useful tool to help people have conversations with their family members or other loved ones about their wishes regarding end-of-life care. We know these conversations can be difficult. Even though people say it's important to have the conversation, we all find lots of reasons to avoid actually doing it.

After we posted the Conversation Starter Kit on our website a few years ago, parents contacted us about the need for an additional resource: **a Starter Kit specifically designed to help parents of seriously ill children who want guidance about “having the conversation” with their children.**

We are not experts in this area, but we are parents; and it is with a lot of humility that we offer this new Starter Kit as a resource to help parents and loved ones begin a conversation with seriously ill children.

the conversation project



Created by The Conversation Project and the Institute for Healthcare Improvement

In some ways, “having the conversation” with a seriously ill child is very different from having the conversation with an adult family member or loved one. It can be hard (or in some cases, not possible) for a child to articulate his or her wishes and preferences. And of course there’s the inherent heartbreak of a seriously ill child. As one parent told us, “When you’re talking about a child, there’s no such thing as a ‘good death.’”

Yet even though the circumstances are very different, the goal is the same: *to understand your child’s wishes to the fullest extent possible, and make sure that those wishes are respected.*

We hope that you find this Starter Kit useful in having conversations with your child, and we welcome your feedback about how we can make the Kit more useful. We are well aware that one size does not fit all — and that “the conversation” will be very different depending on the age of the child (from babies through teenagers), the nature of the child’s illness (from sudden crisis to chronic illness), and the setting (whether hospital or home). Please take what you find useful, start wherever you want, and revisit different sections of the Kit over time.

We also invite you to ***share your stories*** about “having the conversation” with your child on the Conversation Project website at www.theconversationproject.org/your-stories, so that other parents can learn and benefit from your experience.

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Thanks to Dianne Gray, Blyth Lord, Paula Skelley, and Kathy Perko for sharing their stories, experience, and wisdom. Their invaluable contributions are at the heart of this document.

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Step 1: Get Ready

“Should I have the conversation with my child?”

If you're worried that having the conversation with your child might make a tough situation even worse, you're not alone. Most parents of seriously ill children start exactly where you are.

You know your child better than anyone else. And more than anything, you want to protect your child. You might be wondering...

Will having the conversation upset my child?

Will having the conversation frighten my child?

Will having the conversation make a difficult situation even worse?

Is it better for my child not to know how sick he or she is?

Will talking about death and dying make it come true?

It's okay to “go there.”

We have learned from the stories of experienced pediatricians and palliative care providers across the country that children often sense that they are dying even if nobody is talking about it. We often hear that many children don't talk about this because they want to protect their parents! They don't want to upset you. So your child may need your permission to go there. Children are often more open to talking about dying than you might expect, but may bring it up in unexpected ways. Also, research has shown that parents who talk about death with their children do not regret it (but many of those who do not talk about it regret not having done so).

Kreicbergs U, et al. *N Engl J Med*. Talking about death with children who have severe malignant disease. 2004; 351: 1175-86.

Here's the advice of an experienced pediatric nurse...

- **Kathy:** *Oftentimes parents don't want to have this conversation because it will upset their child, and the child doesn't want to bring anything up because they don't want to upset their parents. Somebody needs to bridge that gap. I'll say to the parent, "Why not give it a try."*

And here is the advice of a mother whose child died at age two...

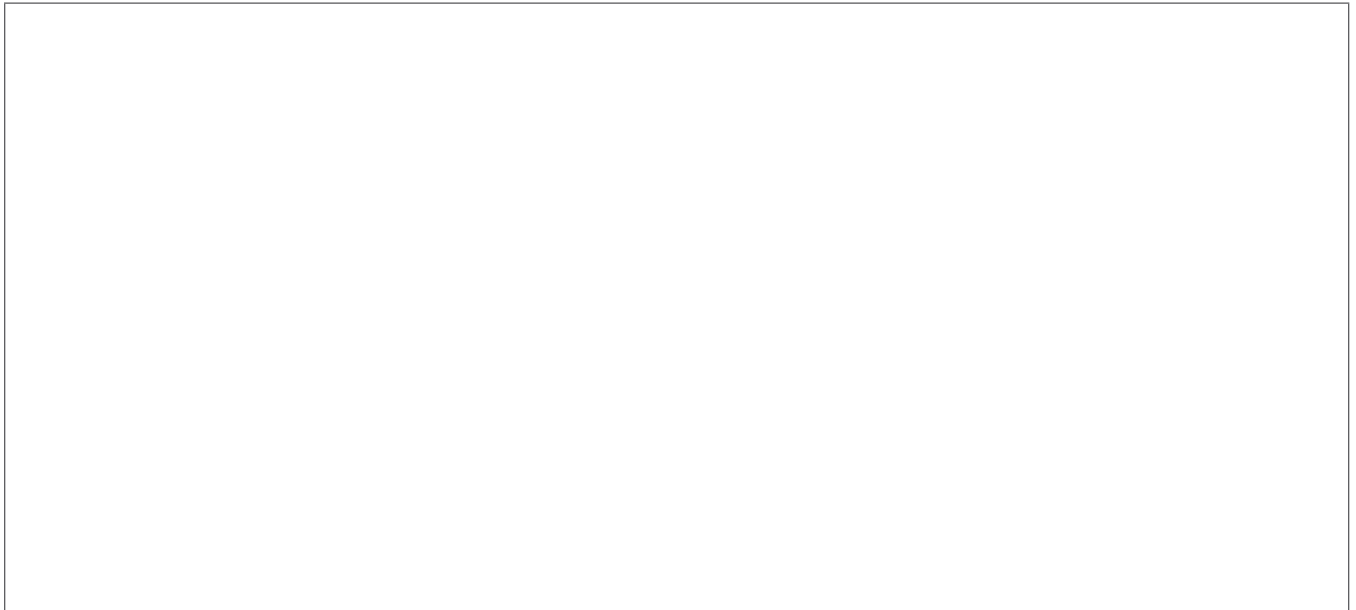
- **Blyth:** *When a parent asks, "Should I have the conversation with my child?," they sort of already know the answer. This is the scariest thing the parent will have to do — if they're fortunate enough to have a child that is able to have this conversation with them. (Unfortunately, some of these children can't communicate.) This is the scariest thing a parent will have to think about doing because they want to protect their child. So the question is how to help them, because they want to talk about it — but they don't want to talk about it.*

So having the conversation with your child — as hard, awkward, sad, and scary as it may be — is really important, and can be helpful for everyone.

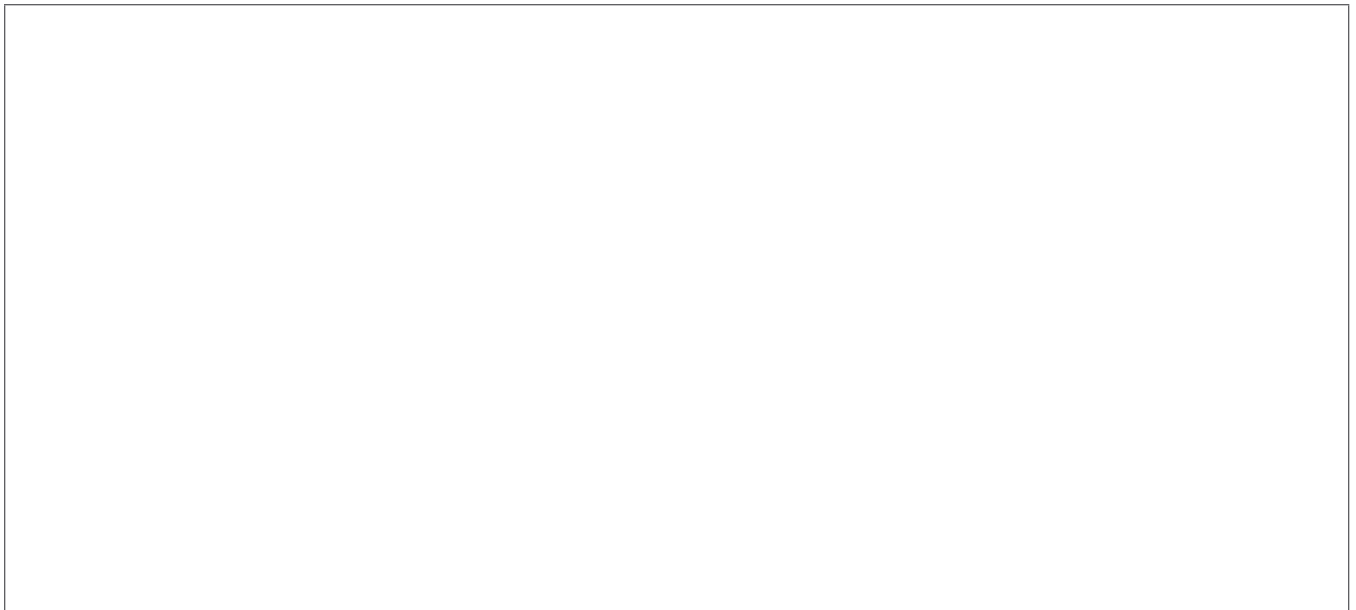
Remember

- It is natural for parents to worry that "having the conversation" might upset their child.
- Children often sense that they're dying even if nobody is talking about it.
- Children often don't talk about it because they don't want to upset their parents.
- Talking about death will not hasten it.
- Even if your child can't communicate verbally, there are often other ways to communicate.
- Parents who talk to their children about death often cope better after their child dies.

What do you need to think about or do before you feel ready to have the conversation with your child?

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What's your biggest fear about having the conversation with your child?

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Step 2: Get Set

“Okay, I’m ready to have the conversation with my child. But how do I start? What do I say?”

There are no right words and no wrong words. We can’t tell you what to do, or what’s right for your child, because this conversation is different for every single child, every single family. But we can tell you what works for some children. (And we would love to hear about what worked or may not have worked so well for your child.)

The important thing is to be open to where your child wants to go — what questions your child has, what they’re thinking about. Listen carefully, and let your child guide where the conversation goes. Sometimes they feel like talking, sometimes they don’t. And sometimes they’re thinking about something that hadn’t even occurred to you.

As a parent, you want to know what matters most to your child... and make sure you’re doing what your child would want.

Your goal is to find out what’s most important to your child — to meet your child wherever he or she may be.

What makes your child uncomfortable? Or confused? Or angry? Or scared?

What does your child want her doctors and nurses to know?

What can you do to make sure your child feels safe? And comfortable?

If your child is in the hospital, does he want to have his favorite stuffed animal?
Or a favorite piece of clothing? Or a picture of a favorite place?

Things will change over time. And children may have different questions on their minds at different times.

Here is the advice of a mother whose child died at age 14...

- **Dianne:** *In many pediatric cases, they go up and down and up and down, and they can be very near death but then rise again. I had to have several conversations with Austin because it looked like he was going to die several times. So, I asked Austin a series of questions to lead him to his own understanding. I asked, "Do you think the doctors will be able to cure you?" And he said no. And I said, "I think you're right." It was really led by him. I would ask the questions, but the understanding was generated off of his responses to me.*

And here's the advice of a mother whose child died at age 9...

- **Paula:** *As parents, I think we sometimes shut children down when they are open to the conversation. If they want to speak about death and dying, we want to comfort them by telling them not to worry—they'll be okay. We need to follow their lead and let them explore the topic of death as we would let them explore any other topic of life. If a child has the bravery to bring up the subject of death, parents should take heart and follow this courageous lead.*

“Well, that’s interesting. What made you think about that?”

Perhaps your child asks out of the blue about Aunt Mary’s funeral which took place two years ago, or wonders aloud where the neighbor’s dog is now (the dog died three months ago)...

- *You could say: “Well, that’s interesting. What makes you think about that?”
Open the door, and see where your child takes you.*

Or perhaps one day your child asks, “Am I dying?”

- *Instead of answering “yes” or “no” — again, you could say: “Well, that’s interesting. What makes you think about that?” Or, “Do you think you are dying?”*

Be open to your child creating memories about her life.

- *She might say, “I’ll always remember how we went to grandpa’s house every year for the 4th of July.” Invite other memories.*

Here are some ways you could start the conversation...

You might reflect aloud upon the loss of someone close to your child — a grandparent, another family member, a pet, etc.

- *“Remember when Grandpa died?” “Remember when Daisy died?”*

If you and your child believe in heaven, you might ask...

- *“Do you ever imagine what heaven is like?”*

You might ask an open-ended question about what’s happening with their illness...

- *“You know, Dr. Jones doesn’t think there’s any more medicine to make your cancer go away...” And see where the conversation takes you.*
- *Or, “Do you think the doctors will be able to cure you?”*

Here are some things you might want to talk to your child about...

- *What would you like me to tell your doctors and nurses about how you want to be treated?*
- *What do you want me to tell them about how you **don't** want to be treated?*
- *What pictures would you like to have nearby?*
- *What music would you like to listen to?*
- *What food do you like best? What food do you NOT like?*
- *Who would you like to come visit you?*
- *What would you like to do?*
- *If you're very sick and may die, where do you want to be?*
- *Are there people you would like your special things to go to?*
- *What three things do you want your doctors and nurses to know about you?*
- *What makes a good day for you? What makes a bad day?*

You might want to print out *"My Wishes"* — a booklet written in everyday language that helps children express how they want to be cared for in case they become seriously ill. It was created by Aging with Dignity, the folks who developed "Five Wishes" and is available at www.agingwithdignity.org/catalog/product_info.php?products_id=85. You could print it out and let your child fill it out. Or if they aren't able to fill it out themselves, you could be their "secretary" and **write down what they want people to know about who they are and what matters to them**. Perhaps it is too much to have your help, so maybe a trusted family member, friend, or hospital staff member can help.

“What do you want me to tell your doctors and nurses about you? And about how you want them to treat you?”

Five things I want my doctors to know about me.

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“What are the three most important things that you want your friends, family, and doctors to know about you and what matters to you?”

Things I really like.

Things I really don't like.

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You might want to help your child create a list of “Things That Matter to Me”

You might want to help your child create a list of things that matter most to her, and post it prominently for all the care team to see.

- *Please don't talk down to me. No baby talk!*
- *Please don't stand around my hospital bed and talk about me as if I weren't there.*
- *Please answer my questions... all of them. And be honest!*
- *Please don't turn on the light when I'm asleep.*
- *Please don't talk loudly.*
- *Please ask before touching me.*

What if my child doesn't want to talk?

If you have a two-minute conversation, and your child stops talking — it's okay. It just means he's done for now and needs some time to digest. Follow his lead. These are hardly ever one-time conversations; they often happen in bits and pieces over time.

The main thing is to let your child know that you'll be there whenever he does want to talk. He can tell you what's on his mind, and you'll be there to listen.

Just let him know that it's okay for him to ask you any question at all, or tell you anything at all. Or just be quiet.

What if your child is a baby or cannot talk?

While in many cases a conversation with a seriously ill child may not be possible, communication takes many forms. There are unspoken conversations between a parent and a child. It's also important for parents to have conversations with each other, and with other family members, to make sure everyone is on the same page. And parents should have ongoing conversations with members of the medical care team to explore preferences and values and guide decision-making.

Here is the advice of a mother whose child died at age two...

- **Blyth:** *Over a period of two months, my husband and I had a series of conversations where we sat down and talked together about our care goals and values for our daughter. What would “quality of life” mean to her and what it would mean to us? What were interventions that she wouldn’t want done to extend her life? How would we know when she was ready to die? And we trusted that we would know it. We said that there would be no feeding tubes, but then we changed that to treat her second pneumonia with an NG tube because we felt that she wasn’t ready to go. We felt this by holding her in our arms, looking at her, looking at each other, and we said she isn’t ready yet. In the third pneumonia, we did the same thing, and figured that the quality of life would no longer be what she wanted so we would not treat this pneumonia, and five days later she died.*

What if I need more help?

There may be some conversations that you will feel more ready for once you have talked to your child’s medical care team in greater detail. You may also want to ask that a member of the care team be present with you when you begin this conversation with your child.

You can always ask someone on your child’s care team for help. You can say, “I’d like to talk to my child about what’s happening, but I’d like some advice and help. Is there someone [a doctor, a nurse, a social worker, a chaplain] who could help me?”

Step 3: Go

Now that you've had the conversation with your child – *not just one, but the first of many conversations*— you have a good idea of what's on his mind, and what matters most to him.

You're in a good position to make sure the team caring for your child knows what's most important.

You're in a good position to make sure your child's questions get answered.

And you're in a good position to make sure your child's wishes are respected.

In short, you are the keeper of your child's wishes — and your child's most important advocate.

This step is about making sure your child's care team knows your child's wishes — and follows them as much as possible.

Research has shown that the more actively engaged parents are in decision making, the more at peace they feel after their child dies. Once you have started conversations with your child, you can be extremely helpful in advocating for your child, or helping her advocate for herself.

If you have questions for the medical team, ask them. No question is too small. Keep asking until you have answers that make sense to you and your child.

Here are some examples:

- *I have some questions I'd like to ask you about my child. Is now a good time?*
- *What does it mean when the machine beeps?*
- *Can you explain what you mean when you say [_____]?*
- *What should I be on the lookout for in the next [hours, days, weeks]?*
- *Could you help me understand the best-case scenario and the worst-case scenario?*

In many hospitals, it is common for clinicians to “round” as a team. Some hospitals invite families to listen to discussions on rounds. If this is not possible, or if your child’s physician is not able to “stop rounding” when you have a question, ask when she can come back.

Often, your child’s nurse or social worker can be called upon to help find a time to have your concerns addressed.

How can I be the best advocate for my child? How can I make sure the care team knows what matters most to my child?

If your child has made a “List” — or asked you to write down their List...

Post your child’s list right by their bedside or on their door.

Encourage your child’s care team to read the list. The care team also wants what is best for your child.

Engage in a discussion with the care team about the items on the list.

Recognize that your child and the care team work together to address what is on your child’s list. Advocate for your child while recognizing that some items could be in conflict with good medical care of your child (not wanting any more pokes or any more tests when they may be vital in providing appropriate care). It is important to come together and look at the list.

If your child has filled out the “My Wishes” booklet — or asked you to be their secretary...

Share it with your care team, perhaps making a copy for them to include in their medical records or to share as your child’s care team members change.

Talk over items in the booklet that you think are particularly important for the care team to know about.

What do I do if my child’s condition worsens?

Make it very clear to your child’s care team that you want them to keep you informed about what is happening with your child. You might ask...

- *How are things changing?*
- *Do you know what we can expect in the next few hours/days/weeks?*
- *Please keep me updated on any changes in my child’s condition.*
- *What decisions about care might come up in the next few hours/days/weeks?*

Step 4: Keep Going

This is the most difficult step of all.

In **Step 1**, you began to understand that “having the conversation” with your child shouldn’t be harmful — far from it. It could be the most important gift you could share with your child.

In **Step 2**, you actually “had the conversation” — the first of many. You listened carefully to whatever your child wanted to talk about, whatever was on his mind — and you let the conversation go wherever he wanted to take it.

In **Step 3**, you embraced your role as your child’s advocate. You made sure that your child’s care team knew what mattered most to your child and your family — and followed your child’s wishes as much as possible. You made it clear to the care team that you wanted them to keep you informed and updated as your child’s condition changed.

In this step, you need to do your most important job of all as a parent: You need to be there for your child as she becomes sicker, and faces death.

What do I say if my child asks, “Am I dying?”

In Step 2, we talked about listening carefully to understand what’s on your child’s mind, and being open to following their lead. If your child asks, “Am I dying?,” keep the door open...

- *You could turn the question back to them. Say, “Do you think you’re dying?” or “What makes you think about that?” And see where they take you.*
- *You might say, “You know, Dr. Jones doesn’t think there’s any more medicine to make your cancer go away.” And see where that takes you.*
- **Dianne:** *In Austin’s case, we said that the doctors are going to continue to try their very best to find a cure, they will never stop, but they may not be able to find a cure in time to beat this disease. The disease might get worse. But the doctors have promised that they will keep you free from pain.*

What happens if I cry in front of my child?

- **Kathy:** *The parent might say, I don't want him to know that I'm sad. And I might say, "Well, you are sad. You're sad because the doctors can't cure his disease, there's no more medicine that makes sense. You're sad because he's going to die before he lives a whole life."*

What if my child is afraid of making me sad. What do I do?

- **Kathy:** *I might say, crying is something we do when we are happy or when we are sad. I ask the child, "Why are you afraid to have your mom cry?" And they might say something like, "It will make her sad that the doctors can't make me better." And then I might say, "She already knows this and she's already very sad and she loves you so much. I wonder if you talk about this if it might make you feel better." That often works. Tears are okay.*

Will talking about death make it come true?

- **Dianne:** *It is important to remind parents that just because you have this conversation does not mean that you are hastening death. I've seen families that think that just because you have the conversation, their child will give up and die.*
- **Blyth:** *That is so huge. The magical thinking that parents do around control for their kids is supersonic. That happens for all people for all ages, but that is especially true for parents who desperately want to have some control over what is happening to their kid. And, the superstition that if I talk about it I'm making it happen is so huge.*

“When death neared...”

■ **Blyth:** *Last week, I heard a parent say she was at peace with her child's death as much as she could be. She said that he died on his own terms. The terms include where you want to die, how alert you want to be. This child slipped away quietly while no one was paying attention and the mom just thought, this is exactly what he would have wanted and needed to do. She believed that he was trying to protect his mother. So he didn't want her to have to say goodbye in that moment so he just slipped away when no one was looking.*

■ **Paula:** *When Lydia broached the subject of death, she'd been battling cancer for a year and a half. She asked, “Do you think God would let me see myself as a teenager if I died now?” “Yes,” I said. “Just ask...”*

That's when I opened the door further, and asked the hard questions. Surprisingly, we were able to laugh a little as we discussed the possibility of keeping an urn with her ashes in the house. Lydia thought that would be “gross.” By the end of the conversation, Lydia had decided where she wanted to be buried, the color of her coffin, and other special things she'd like done at her funeral.

I am grateful we had the hard conversation. Once that was over, the door remained open for occasional questions and discussions over the last six months of Lydia's life. I was able to assure her that although I'd never want to live without her that I would be able to, just as she and I were able to keep living when my mother died the year before. “We had sad days, but we were able to have good days as well,” I said. I could see her contemplate the situation as she remembered the grief process our family had been through.

When death neared, my daughter and I were able to comfort one another and leave nothing unsaid. Lydia was able to tell me when she felt her time was coming to an end. I was able to let her know that I thought Grandma and God would greet her on the other side.

■ **Kathy:** *One of the things that I had to learn is what I think would be a good death isn't necessarily the same for all parents. I would have been devastated if my child died in their sleep. But another mother told me, “How blessed am I that he was so confident in my love that he could slip away without another word.” As a health care professional, I thought, “Note to self”—don't assume you know. Just because it would be the most painful death for me, it was the most blessed death for this mom and her son.*

A word about siblings...

Siblings go through grief in their own way.

- **Kathy:** *You might have four children of different ages, and it might be hard to get them all on the same level of understanding. It is perfectly reasonable for a child to say, “When [my brother’s] done being dead, can we do this?” Or a 16-year-old sibling that closes the door for a while, is okay. We need to let parents know that children need to go through this grief in their own way, and that this will impact them for the rest of their lives.*

- **Dianne:** *Each child within each age group will have a different understanding of what death is. Each child has the right to have this conversation individually and then together as a family. It’s imperative to include healthy children and siblings. Then, if they are comfortable, they should have conversations with the dying child. Encourage the sibling to talk about the impending death. In hindsight, the families that I have spoken with throughout the dying process have been thankful that they have sat down with the sibling to talk about the death rather than not talk about it. And I encourage siblings to have conversations with their dying brother and sister or write them a letter if they don’t feel comfortable verbalizing what they feel.*

- **Kathy:** *The other thing that we will say when children are home on hospice, is to assign an adult to each healthy child — an aunt, a friend, etc. — so that there’s an adult who can just be in charge of those siblings in the couple hours before the death and then after the death. Then the children can be a part of this experience, but they can leave and walk into the backyard for a minute, and someone has their eyes on that child. It lets the grieving parent be really present in that moment. We have worked with children who say, “I can’t be there, I won’t be there. I have to go to school.” You can’t force the siblings to be there, but you can certainly encourage it.*

Resources

Here are some books you may want to read...

***On Death and Dying* by Elisabeth Kübler-Ross**

Just re-released with a new foreword by Dr. Ira Byock; the classic book written following EKR's hundreds of interviews with dying patients. Has helped millions.

***On Children and Death* by Elisabeth Kübler-Ross**

Based on a decade of working with dying children, this compassionate book offers the families of dead and dying children the help — and hope — they need to survive. In warm, simple language, Dr. Kübler-Ross speaks directly to the fears, doubts, anger, confusion, and anguish of parents confronting the terminal illness or sudden death of a child.

***Tunnel and the Light* by Elisabeth Kübler-Ross**

It contains the “Dougy Letter,” which is written to an eight-year-old as a way to explain all of life, which includes death.

***On Grief and Grieving* by Elisabeth Kübler-Ross and David Kessler**

Just re-released with a new foreword by Maria Shriver.

***The Private Worlds of Dying Children* by Myra Bluebond-Langner (Princeton, NJ: Princeton University Press; 1978.)**

“The death of a child,” writes Myra Bluebond-Langner, “poignantly underlines the impact of social and cultural factors on the way that we die and the way that we permit others to die.” A moving drama constructed from her observations of leukemic children, aged three to nine.

The End of Life at the Beginning of Life: Working with Dying Children and their Families by Nancy Cincotta (clinical director of Camp Sunshine and a LICSW) — a chapter from the book, “Living with Dying.”

While the chapter and the book in which it is published are written for a clinical audience (doctors, social workers, chaplains, nurses etc.), parents may find this compassionate, sensitive, and objective discussion of how to support parents and dying children to be helpful. It provides a bird’s-eye view of family dynamics, parent-child dynamics, and provider-parent dynamics. The chapter is especially appropriate for parents of older children who are sick.

Scarlet Says Goodbye by Christine Thompson
Grief/activity book for children.

For Clinicians

Palliative Care for Infants, Children and Adolescents: A Practical Handbook by Brian S. Carter (Editor), Marcia Levetown (Editor), and Sarah E. Friebert. Second Edition. Johns Hopkins Press; 2011.

(Note especially the chapter on Communication.) There are few things requiring more expertise, delicacy, and compassion than caring for an infant, child, or young adult with a life-limiting condition. Written by leading researchers, clinicians from relevant disciplines, family members, and advocates, this practical guide provides professionals involved in pediatric palliative and end-of-life care with comprehensive information in a single volume.

Here are some websites you might find useful...

Children's Hospice and Palliative Care Coalition

www.chpcc.org

Family resources, content-rich site

Communication Counts

www.danya.com/ccounts/cc_individuals.asp

Free downloadable toolkits

Courageous Parents Network

www.courageousparentsnetwork.org

Resources for parents of children with life-limiting illness

National Organization of Rare Disorders

www.rarediseases.org

Content and resources for families of children diagnosed with rare disorders

Please share...

- We hope you will share this Starter Kit with other parents.

www.theconversationproject.org/starter-kit/intro

- And we invite you to share your stories on The Conversation Project website — to help other parents learn and benefit from your experience.

www.theconversationproject.org/your-stories