



Pediatric Starter Kit

Having the conversation with
your seriously ill child



the conversation project

CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

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.**

NAME

DATE

SPECIAL 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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Why talking matters

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 better.

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).

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 frighten my child or make her sad?
- Will having the conversation take away my child's hope?
- Will having the conversation make a difficult situation even worse?
- Is it better for my child not to know how sick he is?
- Will talking about death and dying make it come true?

It's okay to “go there.”

We have learned from the stories of parents and pediatricians 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. 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).

Kreichbergs U, et al. Talking about death with children who have severe malignant disease. New Eng J Med. 2004;351:1175-1186.

HERE IS THE ADVICE OF TWO MOTHERS WHOSE CHILDREN DIED...

Blyth: *When a parent asks, “Should I have the conversation with my child?,” they sort of already know they should. This is the scariest thing the parent will ever have to do — though, unfortunately, some of these children can't verbalize their thoughts.*

Dianne: *So try... and if it doesn't feel like a complete conversation the first time, try again. Most children do want to talk about life in general and, most often, about death. It's natural.*

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."

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? (For example, talk to your spouse, parent, sibling, child's health care provider, or social worker.)**

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

Step 2 Get Set

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

We can’t tell you what’s right for your child, because this conversation is different for every child, every family. But we can tell you what works for some children.

The important thing is to be open to what questions your child has. Listen carefully, answer the question as asked, and let your child guide where the conversation goes.

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.

- What makes your child uncomfortable? confused? angry? sad?
- What does your child want her doctors and nurses to know?
- What can you do to make sure your child feels safe? comfortable?
- If your child is in the hospital, does he want to have his favorite stuffed animal? a favorite piece of clothing? a picture of a favorite place?

As your child’s condition changes, so will your child’s questions. Remember that it’s important to revisit these conversations from time to time.

Reassure your child that you can handle the conversation:

- *It is sad and hard for me to talk about this with you because I love you so much and want you to be all better. But I also know that I can’t control what’s happening with your sickness. What matters most to me is knowing what you’re thinking and feeling.*

HERE IS THE ADVICE OF A MOTHER WHOSE CHILD DIED AT AGE 14...

Dianne: In many pediatric cases, a child's health may appear to get better and worse; it may even appear that he or she is near death, but then improve 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 hear what his own understanding of his condition was. 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 conversation was driven by 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.

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 our dog, 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...
- How do you think your treatment is going?

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

For example:

- *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 DONT want to be treated?*
 - *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?*
 - *What food do you like best? What food do you NOT like?*
 - *Who would you like to come visit you?*
 - *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?*
-

? **Ask your child, what are the three most important things that you want your friends, family, and doctors and nurses to know about you and what matters to you?**

Things I really like.

Things I really don't like.

You might want to help your child create a list of “Things That Matter to Me” and post it prominently for all the care team to see.

For example:

- *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.

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. Most importantly, you should have ongoing conversations with your child's medical team to explore your family's preferences and values to 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.

What if I need more help?

There may be some conversations for which you will feel more ready 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?”

Guidelines for having the conversation with your child’s medical team

Here are some things that the care team will be interested in hearing from you about you and your child:

- *Here is how my child communicates with others, to let them know what s/he is feeling and thinking...*
- *Here is what I understand about my child’s illness...*
- *Given what I understand and know, here is what matters most to me for my child and my family...?*
- *Here is how much information I would like about what is likely ahead with the illness...*
- *If my child’s health condition worsens, here are the most important goals for my child and my family...*
- *My biggest fears and worries about the future, given my child’s condition, are...*

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 or her.

You're in a good position to make sure the team caring for your child knows what's most important, that your child's questions get answered, and that his or her 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?*
- *How is this going to look? (How, ultimately, will my child die — will there be an infection? will there be pain?)*

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 made a list of “Things That Matter to Me” — 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 (for example, 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 review the list.

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?*
- *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 his or her 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 do their best to 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 doing to die so young."*

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? Will it take away my child's hope?

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, of all ages, but that is especially true for parents who desperately want to have some control over what is happening to their kid.*

“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. 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. 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.

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.”

Please share.

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

theconversationproject.org/starter-kits

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

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