

Talking about death

Talking to the dying child about death

No one can tell you what to say to a child about dying. No one can write such a script. It is so much easier not to speak, to pretend that we can protect our child from more pain. We ask ourselves why we should add fear to our child's burden.

But research shows that a child whose condition is getting worse almost always knows that something is very wrong. The child, like you, may pretend not to know because he wants to protect you. Both of you are pretending, both of you are protecting, both of you know something serious is happening.

However, research tells us about children, it does not tell us about **your** child in particular. It cannot tell us about your family. You will choose how and what to say. This is just a guide. It may not fit with your understanding of what is best for your child.

Listen very carefully to your child's comments and questions

Follow your child's lead but know where your response is taking the conversation.

For example: *"Will I get better?"*

- * If you answer *"we'll have to wait and see,"* you will lose some of your chance to talk about it, and miss a chance to give support.
- * If you answer *"sometimes no matter how hard everyone tries, the body can't be fixed."* You leave an opening for your child to ask more or not. (Not all children choose to move ahead right then)
- * If you answer *"no one knows for sure but what do you think about that,"* it allows you to get a sense of what your child is thinking.
- * If you answer *"Sounds like you want to talk about what might happen if you can't get better – do you?"* it will lead right into a discussion.

If you answer *"I've been thinking about it too. Shall we ask the doctor to talk to us about that?"* It allows you to delay dealing with this until you can get some support from a health professional.

Opening the way to a discussion of death allows your child to share her fears. None of us wants to leave a child alone with fears. So we must try to be brave and honest and open in order to give comfort.

Listen for hints that your child wants to talk. Your child needs to know that you are willing to listen, and, that what you say can be trusted. If you never mention the child's illness and the changes in her life, you never give permission for them to be discussed.

Consider talking about death as a process rather than a one time event

- * You may need to give many chances for this conversation. Not every child will ask about death, but every child needs at least a few times when she knows you are ready to hear and answer.
- * Once you have an opening moment, think about your response as taking the first step. You may go only a short way in the first talk, or, your child may prompt you to keep going. You may need to go back over the same ground many times in different ways. These talks can be times when you draw very close to your child, quiet his fears, and explain that what he means to you will not change, whatever happens.
- * Not every child will ask the questions that will allow the conversation to happen. You may need to find different ways for a child to express herself. The child's drawings, stories and play may offer chances to talk about dying in a softer way. You can draw attention to a tree blossoming and talk about life cycles, or clouds that come and go, without moving into any mention of the child's condition at first.

Talk so your child can understand

Children can't understand abstract ideas until they reach their teens. They think in terms of what they can know with their senses. Heaven is a place like the world, God is a person, and so on. A concept of a "soul" may be hard for a child to grasp.

- * Try to match what you say to the real things your child has seen or done.
- * Use simple words and sentences.
- * Be honest and to the point.
- * Manage your child's questions and concerns.
 - ◆ If your child is anxious about the process of dying:
"Does it hurt to die?"
Reassure that doctors and nurses can make things feel comfortable even if they can't make the body well. Ask your child if she wonders about how dying feels. Wait for a response. "*Some parts of the body will work more slowly so you may feel tired and sleepy. You may not want to eat. You may sometimes think you are floating or inside a dream.*"

Children are more likely to ask hard questions if you are open with them and don't change the subject when sad topics come up. If you talk to them about serious things children learn to talk to you in the same way.

These discussions can be very meaningful times with your child. Treat them as precious moments rather than ones you dread. If you have thought about ways to talk with your child, you will be better able to respond with grace. You can prepare yourself by reading some things about a child's understanding of death, by talking to a member of staff, or by talking with your partner about what you want to say.

Being alone is a great fear of most children. Say often and in many ways that you will be with your child when he needs you. He will not be alone. "When you are very tired you can close your eyes and float as if you are resting on a cloud because I will still be here. You will hear my voice."

Parent voice:

I asked my 16 year old how she pictured her death. Her response was wonderful.

She said, "I will either be at Canuck Place (the hospice in which we spent time), with all of you dear people around me, or I will be an old lady on the porch of my house. I will be watching the sun go down with my husband in a rocking chair beside me.

- ♦ If your child asks direct questions about death and beyond "what will happen after I die," you will need to reach into yourself to share your spiritual beliefs with your child.

Parent voice:

I am not a believer in a God or an afterlife so I just didn't know how I was going to answer those kinds of questions. I knew I wasn't going to pretend something I didn't believe. Strangely, the hospital chaplain was really a help. She made me realize that I did believe in a love that existed now between me and my child and would not die. It would remain with me and be part of my life. That love would be a presence in every memory. It would go nowhere. It would stay right here with me. So when the question about life after death came I answered my truth, 'You will go back to where you started – as a feeling of great love inside me.' Of course I had to try to make that idea something a ten year old could understand. I asked several friends to help me with this idea. I came up with images 'like a song that stays in my head', that is what you will become. Another time I suggested that she could become part of me, sharing my life because even now, when we were apart she remained always with me in my mind rather than on my lap.

Spiritual beliefs are not tied to religious beliefs. Here is your chance to also tell your child about your love and the power of memory.

Do tell your child how she will always remain part of the family. You can say something like: "From the very first moment I saw you after you were born, I loved you. We called you - (Name) -You became part of our family. (Name) will always be part of our family. As soon as I think your name you come into my mind - always. When you are at a sleep-over, or in the garden, you are still in my mind and heart. When I look at you here, or your picture on the wall or, the picture in my mind I feel the same love for you. When I think of you I feel that you love me too."

- ◆ Some children, even after serious conversations about death, may talk cheerfully about the future. This stumps many parents. What can one say to “*when I grow up I want to be /do?*” It is not easy to understand what the statement means. It may mean that the child is expressing a simple wish about the future. It may be a roundabout way for the child to ask about what the future looks like when life ends. It may be that the child is not ready to accept what he knows. One response might be to ask “*Do you want to play a story game about being grown up? Let’s think about (or find out about) what it is like to be a fireman.*” By talking about the future in this way, you can go along side the child with honesty.
- ◆ Children sometimes ask the “why me?” question. This is when you might have to answer with the only truth: “*I don’t know. No one knows. It is just not fair that you are sick. No one, not you, or me, or anyone did anything to make it happen.*”
- ◆ Your child may worry about what will happen to her family, pets, even things, when she is gone. If your child wants it, you can involve him in thinking this through. “*We are all going to be sad even if we keep you close in our memories. What shall we try to do to make us less sad? What would you like me to do with your special things? You can think about it and tell me when you have an idea.*”

Be ready to manage your child’s reactions to talking about death

You and your child may feel a sense of closeness and the comfort of having shared feelings that were not allowed up to now. It is also possible that either of you could feel terrible grief. Grief can show itself as rage or deep distress. Hold your child through it so he feels your sympathy and abiding love. After a time, do some activity to bring him back to a more even emotional state. You can read a story or watch a videotape together. The message of this is that there is still a life to live.

End note:

Sometimes it is just too hard for a parent to talk about death with the child. There are people on the health care team who can help. The chaplain, social worker, a nurse or doctor can be your partner in this. You may need their support, especially with youths, who may be caught in complex feelings like anger about their fate, a desire to protect their parents, or a rebellion against the choices others are making for them.

Parent voice:

I was dreading the conversation about death. I had to plan it with help from the nurse and some books. I rehearsed it in my mind. I started by reading the book Water bugs and Dragonflies one evening. It went so much better than I had thought possible. It brought us closer. I don’t regret any of the talks we had. We had quite a few about death in the last weeks.

This pamphlet is the result of a collaboration between
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