

Talking about death

Talking with siblings

Your other children will sense your great distress and will be anxious for all the family. Most parents realise this and try to give everyone the love and comfort they deserve. Finding the energy for siblings' needs may be very hard but it is important.

Just as you listen for signs that the dying child wants to talk about the dying, listen for these same questions and signs from the siblings.

In summary:

- ♦ answer questions about the illness or dying simply and honestly. Don't burden children with details.
- ♦ Try not to confuse with terms like "losing her" or "being taken from us".
- ♦ It is better to use clear words like "body is so sick that it can't work well anymore. If it stops working then —will die."
- ♦ Not all children can express their feelings or questions with words. Use play and drawing and storybooks as a "way in."

Be prepared to open the topic yourself if the siblings do not ever mention their worries about their sick brother or sister

This script is a guide. Adapt it or create one that works better for your children. Remember that the health care professionals are very willing to help you if you need them.

"The doctors are finding it very hard to help _____. There are parts of her body that are not able to work anymore no matter what medications or treatment we give. It seems that her body is getting ready to die. None of us can help what is happening in her body. What we can all do to help is make our time together as a family the best it can be. We can try to enjoy each other, help each other, and show our love and caring for each other."

Consider whether a sibling's behaviour might be reflecting emotional stress

(It will be useful to read the section on "Emotional Distress" in the handout Parenting a dying child.)

Sibling voice:

When my brother was sick, I felt lonely. Everyone was sad and tired all the time. I had to do things on my own or with other kids' families. I felt like I wasn't important in my own family anymore.

Many of the suggestions we offered around talking with the dying child, also apply to siblings. It may help to review them.

Not all difficult behaviours can be explained as stress from the illness of the sibling. This is only one part of life. There are many other stresses in children's lives. But you should take account of the special stresses of the illness.

* **Defiance** may be:

- ◆ A way of getting **attention** from, or punishing, a parent who has withdrawn.
- ◆ An effort to get oneself punished in order to deal with **guilt**. There are some children who think that they might have caused their brother's condition by their thoughts or actions. Their thinking might go something like, *"I wished a bad thing would happen and it has come true. It's too risky to admit this but I do need to be punished."*
- ◆ Taking advantage of lack of firm limits from parents who feel that they "have to allow more in this time of stress." (Think about the limits you set on behaviour as being a safety fence. Taking it down leaves the child insecure. But you may want to extend boundary lines a little at this time.)

* **Denial**. The sibling may refuse to talk about or listen to you talk about her sick sibling. She may do nothing to help and even stay away from her. This is fairly common among youth who keep their feelings to themselves. Denial may be quite hurtful to parents and to the sick child. It looks like the child does not care because she lives as if nothing has changed in the life of the family. It is important to try to help this sibling find a way to participate so she can share some precious moments. It is just as important not to force the child to face up to this great sorrow. Some children can cope in no other way than by turning away.

* **Angry outbursts**. These may be:

- ◆ A build up of resentment against parents, the sick child, or the world in general.
- ◆ A build up of tensions held onto inside that then explode in tantrums. It is not unusual for a young child to be angry with the sick child. This is upsetting for you, but try to be understanding. You can respond by reflecting the feeling, *"You're angry are you? I feel angry too quite a lot. I know it doesn't feel good around here some days. It is OK to let the anger out, but not with hurting your sister. Let's think about how else you can let it out."*
- ◆ The anger may switch to love after the "vent" and then anger again. Young children move easily from one feeling to another. They may feel bad, mad or sad and ten minutes later want to go out to play with friends. This is normal and healthy.

Because of normal sibling rivalry, a child in the family may feel he is to blame.

One child said, *"I really got scared when my parents stopped caring about how I behaved!"*

Siblings may need some help from an adult friend or a counselor. Ask a healthcare professional for advice setting this up.

A young adult looking back on this time said, *"I remember feeling how unfair it was that no one paid any attention to me. I felt as if I didn't count."*

- * **Cries a lot, hangs around doing nothing, shows no interest in school, friends and activities.**

This may be loneliness, sadness or even depression.

- ◆ Try to include the siblings in the care of the child without insisting on it. Suggest some things he can do for the sick child. Even very young children can help. *“Can you be the one who makes sure your sister’s teddy is on her bed? Can you read a story each day? Can you keep the glass full of juice?”*
- ◆ Connect to your other children’s lives. Take a short time each day to ask about something important to them, *“How did you do on the test? Did you have fun at the party?”* Taking an interest in the concerns of your other children shows that as you give love to the child whose life is ending, you do not withdraw from the child whose life goes on.
- ◆ Try hard to play and have some fun as a family. This is to allow your other children to be children. It will help them be generous and loving to the sick child. This does not mean you put on a false happy face. It just means that you show that in the midst of great sadness there can be times of joy. Joy is not wrong.

- * **Worries a lot, can’t sleep, clings and acts less grown up than you expect.**

- ◆ Children may feel very insecure. Life is “on hold.” The routines that gave a sense of security may all have changed.
- ◆ There may be bickering, crying, anger, silences between parents who, before this, were strong and in control of things. It is disturbing for a child to witness a parent’s despair. It is helpful if you can explain what your child is seeing. For example: *“This is a hard time for all of us. I am upset because we are not able to make - better. When I am crying it isn’t you who has made me sad. When I am angry it is not at you. I love you and - very much. It is O.K. to feel all these feelings and to show them. We can give each other hugs to show we care. I will come and ask for a hug when I need one. You can ask too.”*

“Daddy and I shouted at each other because we were tired. We didn’t try hard enough to speak nicely. We will feel better after we have a rest. Can you read quietly in your room while we sort out our problem?”

Sometimes it seems to a sibling that the only things that get any attention are the concerns of the sick child.

Make sure the siblings know that it is OK for them to continue their sports and other fun activities. These may be key outlets that support their ability to cope with the stress in the home.

- ◆ Fear may take the form of worrying about his own health or that of the parents. You can reassure your child that most people do not die from their sicknesses. They get better. Most people live a very long time.
- ◆ Death, because it is so hard to understand, can be imagined in fearful forms. (See the reference list for some resources for explaining death to children of different ages.)

School

School age children spend many hours at school. It may be the place where siblings have a period of distraction from home concerns. It may be the easiest part of the day for them. School is also sometimes a real pressure for the siblings who are tense and fearful and not able to focus attention on their work. They may slip behind or develop behaviour problems. We suggest you talk with your child's teacher and/or school counsellor so that he can offer support and understanding.

End note:

You are a person, not a saint, so forgive yourself when you can't be the ideal parent we write about here.

Allow your grief - sadness, anger, frustration - to show, not all the time, but enough. This permits your children to accept their own feelings. A parent who is under control at all times suggests that the children should be this way too.

"Daddy has a pain – will he die too?" "I am sick, maybe I won't get better". Young children will need reassurance that this will not happen to them or to you.

Just keep talking to your children about feelings, including how much you love and care for them. Show this in whatever way you can.

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