

TALKING WITH CHILDREN ABOUT DEATH AND DYING

Important Considerations

- What has the child been told about the disease, prognosis, etc.?
- What is the patient's comfort level with the child knowing details about the disease, prognosis, etc.?
- What is the culture in the family regarding illness, speaking openly, sharing difficult things with children?
- What is the child's history with death—other family members, friends and pets?
- What are the family and child's coping responses related to illness, death?
- If the patient is not living in the same home as the child, when was the last time the child saw the patient?
- What does the child know about the disease?
 - Has the child attended conferences with the doctor?
 - Has the child accompanied the patient to chemo or radiation treatments?
 - Has the child visited the patient in the hospital?
 - Has the child assisted with any care giving?

If the family chooses not to talk with the child about circumstances...

- Always consider the culture of the family, including ethnic and religious beliefs and practices.
- Educate that the child may overhear conversations and imagine things that are worse than the truth.
- Children may also be picking up on the emotional atmosphere in the home and the changes in lifestyle that have occurred as the family has adjusted to the illness.

TOOLS AND LANGUAGE FOR GUARDIANS TO SUPPORT CHILDREN WHEN THERE IS A NEW DIAGNOSIS OF A TERMINAL ILLNESS

Inform the child that there is important information about the medical condition that you want to share with them. This honors the child's importance in the family. *Example: "I went to the doctor today, and he told me some hard news about my cancer. It feels important to me to share this information with you."*

Allow some choice and control about when they would like to hear the information, if possible. Some kids may need a break after simply hearing that there is hard news. *Example: "Would you like for us to talk about it now, or would prefer a different time?"*

Tell the truth using correct medical language. *Example: "You know I've been taking a medicine called chemotherapy. The doctor told me today that my cancer is still growing and this medicine isn't working anymore. I am going to die from the cancer."*

Answer questions the child has. Provide honest, simple answers. If you don't know the answer, it's okay to say, "That's a really good question, but I don't know the answer either." "Can we talk more about that later?"

Reassure the child that their needs will continue to be met by the other people in their lives who love them. Children may need to hear names of these people, and should definitely be told if there will be significant changes in their life. *Example: "You know grandma has been staying with us and helping while I've been sick. When I die, she will move into our house to take care of you."*

Causation and contagion. Remind children that they did not cause the illness, and if it is true, that they cannot catch the illness. *Example: "Remember that nothing anyone did caused me to get the cancer; even doctors don't understand what causes cancer to grow." "Remember that cancer isn't a sickness that anyone catch."*

If the patient is discharged home, be aware that keeping a child's routine as normal as possible is helpful, and talk openly about any changes to their routine. It's also good to find ways to involve the children in simple care giving tasks.

LANGUAGE FOR AN IMPENDING DEATH OF A LOVED ONE IN THE HOSPITAL

Inform the child. It's helpful to have a sense of what the child already knows, so the information you share simply brings the child "up to date" when something changes. *Example: "There's some thing hard I need to talk with you about. It has to do with your father's illness. You know that he has gone to the hospital before and been able to come home. This time, he is not going to be able to leave the hospital. The doctors have done everything they can to try to make him better. His body is too sick, and he is going to die soon."*

Choices about visiting and saying good-bye. Adults often ask if it would be better not to bring the child to the hospital because of the current visual and/or mental state of the patient (i.e., tubes, disorientation, comatose state). It's important to consider allowing the child to have choices, but be assured that there is not a right or wrong choice. Also, in order to make a decision, the child needs information about what to expect. Children usually give details of what they would like when given adequate information. Remember to use concrete medical language. *Examples: "Your father can't speak. He has a tube in his neck that is helping him to breathe." "Would you like to go into the hospital room to see him?" "Are there things you would like to say to your father?" "It's okay if he doesn't talk to you; he can still hear you." "This will be the last time you will have a chance to see your father's body." "If you would like some time alone in the room, I will try to arrange that."*

Allow questions and answer them truthfully. It's always okay to say, "I don't understand either," or, "I don't know the answer to that, but I'll do my best to give you more information."

Reassure the child that they are loved and will be taken care of. Give the child feedback about the significance of the relationship they have with the person who is dying. *"Your father has been fighting this cancer for a long time and hoped he could get better. He didn't want to leave me or you. We both love you very much, and I will continue to take care of you."*

Causation and contagion. Remind the child that no one caused the illness and, if true, that they cannot catch the illness.

LANGUAGE FOR INCIDENTS OF A TRAUMATIC EPISODE OR SUDDEN DEATH

Inform the child using simple details. Give general details of how the death occurred. You can begin the conversation by saying, "Something really hard happened today." **See examples of specific episodes below.**

Sudden death: "Dad's heart stopped beating today, and he died."

Accident: "Mary was in a car accident. Her body was very badly hurt, couldn't be fixed, and she died."

Old age: "Grandma had gotten very, very old, and her body stopped working."

Terminal illness: "Because the disease couldn't be stopped, your dad got very sick and his body stopped working."

Stillbirth: "Sometimes something causes a baby's body to stop working before it is born. We don't know why, but it is nothing anyone did or didn't do."

Homicide: "Your mother was killed today."

Suicide: "Your brother killed himself. Sometimes a person's mind gets very sick and doesn't work right, and they don't understand things clearly. They may think the only way to solve their problems is to stop living, so they kill themselves. However, this is never a solution to problems. The only reason they thought of it is because their mind was too sick to think clearly. It's not anyone's fault that this has happened".

Allow questions and answer them truthfully. Children process information concerning a traumatic death in small increments. Depending on the developmental maturity of the child, he/she may ask for graphic details. Answer the question asked as simply as possible without elaborating with further information. In the case of questions about a murder, it is helpful to refer to the person who committed the act as the "killer" instead of "a very bad person." "Mary was shot by a killer." Children are often repetitive, asking the same questions over and over. Keep answers simple and consistent. This helps to build trust and reassurance that you will continue to tell them the truth.

Reassure the child that they are loved and will be taken care of. Acknowledge the significance of the relationship and the impact the death will have on the child. "Your father loved us very much. I will be here to take care of you." Often children become afraid that another caregiver may die too. It is helpful to reassure a child. "Most people do live for a long time. I plan to continue taking good care of myself."

Causation. It's important that children are reassured that they are not at fault, especially if the death involves an accident that they may have seen or been a part of. "Sometimes horrible accidents happen. There's nothing that anyone could have done to change what happened."

