



Talking to children about life limiting illness

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Case: The patient is a sixty-five year old woman who has severe heart failure and pulmonary fibrosis. She was admitted because of shortness of breath and a fever. After a few days it became clear that she was unlikely to get better, and she asked that the healthcare team focus on comfort. The Palliative Care team was asked to see the patient and her family. When we asked whether there were any grandchildren at home and how they were doing, the youngest daughter burst out crying. "I am just not sure what I should tell me my five year old, seven year old, and nine year old children," she said. "They are so close to their grandmother. They know that something is wrong and seem really upset, but I am not sure how to talk to them."

In today's acute hospital, we often forget about the children and the effect of the illness on them. It is important to ask if there are children at home, how they are doing, and whether the family has any questions on how to talk to them about serious, life-limiting illnesses. Talking to families about this requires a knowledge of children's developmental understanding of death and dying. The following generalizations can be used to guide health care providers.

0-2 years (Infant) – Children at this age have no cognitive understanding of death. However, grief reactions are possible and separation anxiety is a concern. Behavioral and developmental regression can occur as children have difficulty identifying and dealing with their loss; they may react to the distress expressed by others.

2-6 years (Preschool) – Preschool age children see death as temporary and reversible. They interpret their world in a literal manner and may ask questions reflecting this perspective. They may believe that death can be caused by thoughts and provide magical explanations, often blaming themselves.

6-8 years (School Age) – At this stage, children understand that death is irreversible but do not believe that it is universal or could happen to them. Death is often personalized. Expression of anger towards the deceased or those perceived to have been unable to save the deceased can occur. Anxiety, depressive symptoms, and somatic complaints may be present. The child often has fears about death and concerns about their and their loved ones' safety.

8-12 years (Pre-adolescent) – Children at this age have an adult understanding of death – that it is final, irreversible, and universal. They are able to understand the biological aspects of death as well as cause and effect relationships. They tend to intellectualize death as many have not yet learned to identify and deal with feelings. They may develop a morbid curiosity and are often interested in the details of the dying process, and they are interested in religious and cultural traditions surrounding death. The ability to identify causal relationships can lead to feelings of guilt; such feelings should be explored and addressed.

12-18 years (Adolescent) - Adolescents also have an adult understanding of death. They are developing the ability to think abstractly and are often curious about the existential implications of death. They often reject adult rituals and support, and feel that no one understands them. They may experience strong emotional reactions but have difficulty expressing feelings.

Strategies for helping a grieving child are complex and depend on the specific circumstances. However, the following guidelines may help:

1. Express an interest in the child's day; find out what they are doing, how they are doing, and what they are thinking. This will help you better understand where they are in the grieving process and what their beliefs and views are.
2. Work to make keep things as normal as possible [e.g., maintaining family rituals such as Friday night supper or Monday night pizza]. Routines are helpful for children, as they reassure them that the world is not going to change.
3. Welcome all questions, but don't force discussions. Make sure you understand the real question before answering; take your time to think about how you answer. Avoid euphemisms that may confuse the child.
4. Overhearing bad news is the worst way to hear it. Talk with the child from diagnosis onward, and be sure to give updates when there are changes in prognosis or treatment.
5. Prepare the child for visits to the sick person; describe what they are likely to see, and bring along another adult so the child can leave when he/she wants to. Think about bringing along markers and paper so that the child can leave the sick person a message.
6. Talk with the child's teacher or guidance counselor to alert them of the situation. Ask the teacher to let the parent know if the child seems worried.

The most important predictive factors of children's successful outcome after suffering a loss are the availability of an adult and the provision of a safe physical and emotional environment.

The generalizations and strategies provided serve as framework when helping children deal with the death of a loved one. When in doubt, seek help from pediatricians, mental health professionals, and others specializing in bereavement.

There are a number of excellent resources in the community that can be helpful to parents. We recommend The Caring Place (888-224-4673), and The Good Grief Center in Pittsburgh (800-923-9360). The following books are also useful: Kroen, W. C., *Helping Children Cope with the Loss of a Loved One*, and McCue, K., *How to Help Children Through a Parent's Serious Illness*.