

TOPICS IN REVIEW

“What do we tell the children?”

Understanding childhood grief

In the United States, 5% of children by age 16 years experience the death of a parent.¹ Primary care physicians who work with bereaved families thus need to understand childhood grief.² In clinical studies, the most commonly encountered issues include fear of being abandoned, fear that other loved ones or themselves might die, guilt over actual or imagined misbehavior, and difficulty in school or in bonding with new caretakers.^{3,4} We provide practical answers to common questions that primary care physicians and their patients posed to a child psychiatrist who specializes in life-threatening pediatric problems.

LITERATURE SEARCH

We conducted a literature search of the MEDLINE/HEALTHSTAR [Health Planning and Administration/Health Services, Technology, Administration and Research] and PsychINFO databases (1990-2000) using the keywords *childhood bereavement* [and] “exact subject human” [and] “language English.” Older literature and children’s books came from an extensive library on grief accumulated during 15 years of working with children with cancer, trauma, and organ transplantation.

QUESTIONS ASKED BY BEREAVED CHILDREN’S PARENTS

“My wife died in a plane crash while on a business trip. What should I say to our 2-year-old son? My relatives think I should not say anything but should have a female relative move in with us.”

Piaget’s research found that infants and toddlers (about 0-3 years old) understand events in terms of direct experience. The emotional expression and dependable presence of loved people are more important than the words used. Applications of Piaget’s work have found that even preverbal children can tell from the distress of the adults around them that something terrible has happened and are aware of the absence of a loved person.⁵ Thus, not telling a young child about the death of a parent only serves to prevent discussion of what is uppermost in everyone’s minds, rather than protecting the child from pain, as intended.^{3,6} Some cultures—for example, some Japanese, Indian, Armenian, and Iranian cultural groups—believe that bad news is potentially damaging to people. Parents from these groups may have difficulty sharing this information with their children. A physician cannot force honesty but can encourage parents to gradually communicate with their child.

Summary points

- Children have the same tasks as adults in the grieving process, but their developmental stage, relationship to the deceased, and circumstances of the death affect their reaction
- Bereaved children may be afraid of being abandoned or that other loved ones or they may die. They may feel guilty for actual or imagined misbehavior and have difficulty in school or bonding with new caretakers
- Very young children understand that something terrible has happened when a parent has died or is seriously ill, even if they are not directly told. Withholding this information is not protective and prevents appropriate support
- It is best to let children participate in the decision whether to attend the funeral of a family member. If they go, someone should be with the child to provide emotional support and to leave with the child if necessary
- Children benefit if their usual activities—school and otherwise—are maintained as much as possible after a significant loss. Resist the impulse to make a new start

Research with infants and toddlers has led to a description of normal egocentrism; children are likely to view any event as the result of something they did or a volitional act on the part of an adult—because adults are seen as “all-powerful” and can do anything they want.⁷ It is, therefore, important to reassure the child in the case above that Mommy did not want to leave her and that Mommy’s death was not related to anything the child did or said. Children can feel less isolated when the adult bereaved family member talks about feelings with stories and photos.^{8,9} Clinical experience suggests that simple explanations, which often need to be given repeatedly, are useful, but attention to the practical consequences of the loss is vital. If Mommy was the primary caregiver, the absence of the functions she served, or the different way that others fill those roles, will be difficult for the young child. This is true even if a family member is immediately brought in or a wonderful housekeeper or nanny is hired.

Trauma research has found that the death of a loved one that is repeatedly revisited on the television or in newspapers is difficult for all concerned.¹⁰ It is not necessary for the young child to see these news items, and indeed, they may be worth avoiding as a family during the

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Competing interests:
None declared

West J Med
2001;174:187-191



Tim Booth/Images

Communication and emotional support are vital provisions for the grieving child

initial bereavement period. However, it can be useful for a young child to have some of the newspaper articles cut out and saved for when the child wants to know more about the mother.

“My 4-year-old keeps asking when her grandmother is coming to visit. She knows her grandmother died last fall. Why can’t she accept that?”

Preschool-aged children (about ages 3-6 years) were found in Piaget’s studies to have “magical” explanations for events because they do not think in logical sequences.⁵ They generally have difficulty grasping that death is not reversible⁷ and may irritate grieving adults by repeatedly asking about dead relatives or pets. Anticipatory guidance by the physician to the parents about this can be extremely helpful.¹¹

Families often find it easier to help a child deal with the death of a grandparent than the death of a sibling or parent. Grandparents are in an age group where death is more expected and therefore acceptable. They are often less involved in the day-to-day process of the child’s life, so there are fewer changes and reminders of the absence. However, for some children and cultures, the grandparent may play a central role in the child’s life and in the fabric of the family. The loss may have had wide-ranging effects,

which are first apparent to a physician as regression or behavioral problems in the child.^{2,11}

Children of preschool and kindergarten age have been found to understand illness primarily by contagion, and they do not have a clear concept of cause and effect.¹² Children in this age group may need reassurance that they cannot “catch” the sick family member’s illness. It can also be useful to point out that most illnesses are not serious, so that a child does not become unduly concerned over the next doctor’s visit or an illness in the family.¹²

“Should my 7-year-old go to her brother’s funeral?”

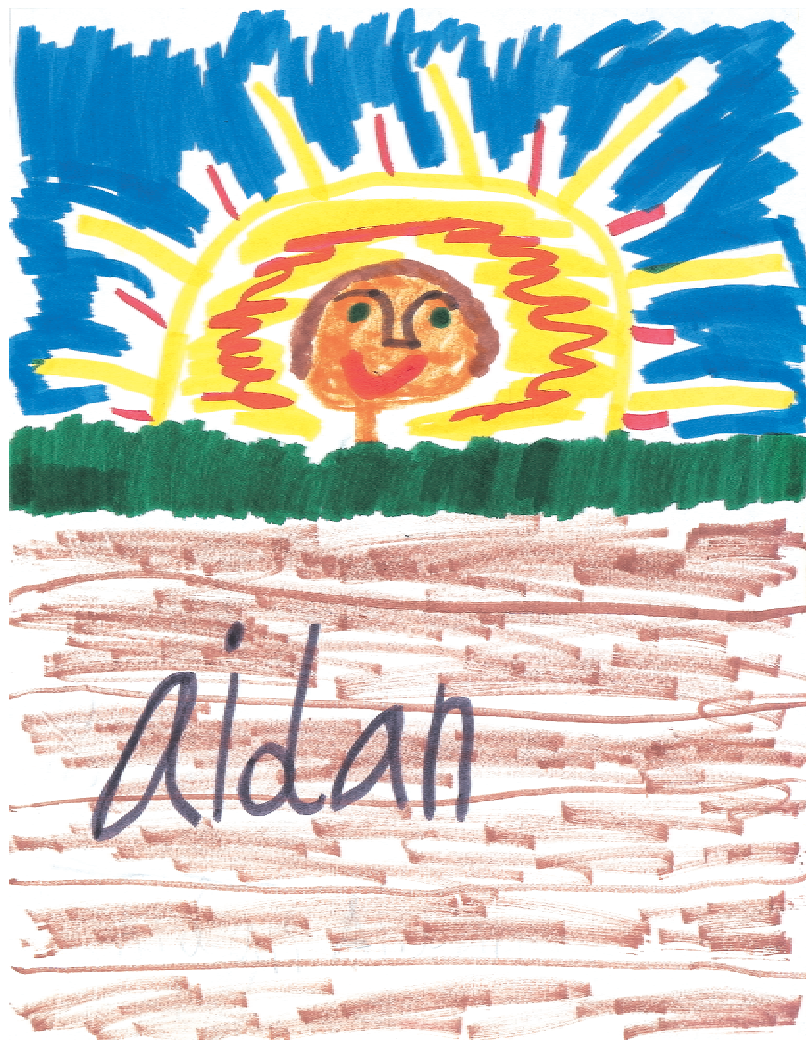
Studies with children from a variety of countries have found that elementary school-aged children (about 7-11 years) are able to understand that death is permanent.⁷ However, a child will not necessarily grieve in the same way that we are accustomed to seeing in adults. Clinicians note that children may appear perfectly happy and normal at times and simply regressed and angry at other times, rather than sad.⁹ They may also go through phases of grieving, appearing to have “gotten over it,” and then suddenly asking questions or expressing sadness or fears. These are normal but much easier for parents to deal with if they are expected.

Funerals and other formal grief rituals aid in keeping the deceased in memory and provide occasions for the bereaved to be supported in their mourning.^{2,4,11} Excluding children from family grief rituals such as a funeral can be devastating, leading to a sense of isolation or even guilt. Children know that an important event is happening that they are inexplicably forbidden to attend. On the other hand, forcing children to sit in a room with hysterical adults or to kiss a dead body can leave lasting traumatic memories. It is best to let children participate in the decision whether they should attend the funeral.⁴ If they go, someone should be with the child (or even adolescent) to provide emotional support and to leave with the child if necessary.^{2,13} If possible, this should be a close friend or family member who does not need to attend the funeral and can be fully available to the child.

Mourning rituals are common in many religious and cultural groups.¹⁴ These rituals provide a structure for grief that can be helpful to both adults and children. However, some modifications may be needed for young children, who may not be able to understand what is expected of them for an extended ritual, such as the Jewish ritual of sitting shiva, which involves 7 days of mourning. Children can be included in formal remembrance of the loss by participating in specific rituals or in less formal ways, such as planting a tree, offering a favorite object, or drawing pictures.⁸ Birthdays, holidays, and anniversaries of the death provide natural opportunities to remember a loved one.² Parents and children can use these natural reminder times to look at family videos or photos or go to the cemetery.¹⁵ Ongoing discussion of the loss provides the opportunity for children to reinterpret the death over the years as their cognitive comprehension grows.²

“I am just starting chemotherapy for leukemia. The prognosis is not good, but I am not dying, at least not right now. How should I explain this to my 11-year-old?”

Clinical experience shows that the difficult issue in this situation is what to say when a child asks, “Are you going to die?” It is important to acknowledge that this is a reasonable question and that death is one possible outcome. Often parents will respond with something like “Not if I can help it!” or “Some people die of this, but I am working with the doctors to beat this thing.” This helpfully conveys information and the parent’s attitude toward the illness. The parent’s delicate task is to facilitate open communication without burdening the child with excess information or decision making.¹⁶ A useful arrangement is for the parent to agree to keep the child up to date about the situation, including events that are of concern. This saves the child from constantly having to interpret the seriousness of the situation from the parent’s mood or other “clues.”



Open communication is an important part of the therapy for a young girl whose mother struggles with a life-threatening illness

It is also helpful if the other parent is sensitive to the child’s need for reassurance that the parent will continue to be around, whatever happens to the ill parent. It is not realistic to say “nothing will happen to me,” but the other parent can say, “I am well and taking good care of myself,” and “We have made sure that there will always be an adult to care for you,” giving the details.¹⁴ In many Latino and Asian cultural settings where there is an extended family involved with the child, or in families who are supported by an active religious organization, the presence of other familiar and significant adults offers security to the child.

Children in this situation commonly experience teasing from peers. Although this is often explained by the cruelty of children, it is more helpful to see it as a fear reaction. The other children are trying to distance themselves from the possibility of such a thing happening to them by seeing the affected child or parent as somehow different from them. Explanations by the child’s teacher or a school counselor can help normalize the situation for the



Bright colors and the sun form a dramatic frame to a woman's face in this drawing by a girl in elementary school whose mother had cancer

child's classmates and mobilize the other children to become supportive or protective toward the child.¹⁷

The chronic nature of cancer treatment and the often-deteriorating condition of a parent means that a child will experience many changes in his or her life even if the parent recovers. Children will be dealing with loss at a time when the family system is stressed, and the family may not be sympathetic to how upsetting it is to children to miss activities or special events.¹⁵ Children are helped if their usual activities—school and otherwise—are maintained, although adults often want to make changes and have a new start.² If possible, an adult who is not personally touched by the illness, such as a scout leader or coach, can be an excellent source of support for a child.

CONCLUSIONS

Even though communication, sharing, and having a supportive family are related to positive long-term adjustment

to bereavement, parents often avoid communicating with children about death. This is because the responsibility of informing children about the potentially life-threatening diagnosis or death of a family member has been primarily left to parents, who are often without guidance about how, what, and when the child should be told. Primary

More books about death for children and adults

For younger children

- Blackburn LB. *I Know I Made It Happen*. Omaha, NE: Centering Corporation; 1991.
- Clifton L. *Everett Anderson's Goodbye*. New York: Henry Holt; 1983.
- Hazen BS. *Why Did Grandpa Die? A Book About Death*. Racine, WI: Western Publishing; 1985.
- Kohlenberg S. *Sammy's Mommy Has Cancer*. New York: Magination Press; 1993.
- Sanford D. *It Must Hurt a Lot: A Child's Book About Death*. Hong Kong: Multnomah Press; 1986.
- Scrivani M. *I Heard Your Mommy Died*. Omaha, NE: Centering Corporation; 1994.
- Shriver M. *What's Heaven?* New York: Scholastic; 1999.
- Vigna J. *Saying Goodbye to Daddy*. Morton Grove, IL: Albert Whitman & Co; 1991.

For older children

- Kremetz J. *How It Feels When a Parent Dies*. New York: Alfred A. Knopf; 1992.
- LeShan E. *Learning to Say Good-Bye: When a Parent Dies*. New York: Avon Books; 1976.
- Richter E. *Losing Someone You Love: When a Brother or Sister Dies*. New York: Putnam's Sons; 1986.
- Simon N. *The Saddest Time*. Morton Grove, IL: Albert Whitman & Co; 1986.

For adults

- Feinstein D, Mayo PE. *Mortal Acts: Eighteen Empowering Rituals for Confronting Death*. New York: HarperCollins; 1993.
- Grollman EA, ed. *Explaining Death to Children*. Boston: Beacon Press; 1967.
- Huntley T. *Helping Children Grieve: When Someone They Love Dies*. Minneapolis: Augsburg Fortress; 1991.
- LaTour K. *For Those Who Live: Helping Children Cope With the Death of a Brother or Sister*. Omaha, NE: Centering Corp.; 1983.
- Mellonie B, Ingpen R. *Lifetimes: The Beautiful Way to Explain Death to Children*. Toronto, Ont: Bantam Books; 1983.
- Rudolph M. *Should the Children Know? Encounters With Death in the Lives of Children*. New York: Schocken Books; 1978.
- Russell G. *Essential Psychology for Nurses and Other Health Professionals*. New York: Routledge; 1999.
- Silverman PR. *Never Too Young to Know: Death in Children's Lives*. New York: Oxford University Press; 2000.

care physicians can help grieving families respond to the children's needs, considering their developmental stage, relationship to the deceased, and the circumstances of the death.

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- 8 Gibbons MB. A child dies, a child survives: the impact of sibling loss. *J Pediatr Health Care* 1992;6:65-72.
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