

HIV: Helping Your Child Understand the End of Life

Many children living with HIV infection have suffered the loss of a loved one. People experience many deep emotions when they are faced with the fact that a loved one is dying. Parents and caregivers often find that trying to explain the end of life to a child feels like a difficult task.

This handout was created to give you, the caregiver, an overview of the general concepts surrounding the end of life and how children at different ages understand death and dying. It offers guidelines to help you talk to your child about the end of life, as well as information about how your child may grieve and how you can help him in his grief. It also offers suggestions about how and where to learn more.

Why should I talk to my child about the end of life, dying and death?

It is natural to want to protect your child from painful or difficult feelings and not talk to her about someone who is dying. However, children sense when you are upset — which, if not explained, can be scary for your child.

Even though talking to your child about death and dying can be hard, it is important that you do so. Whether it is about the death of a loved one or your own death, you need to talk to your child, because being open about all aspects of life is part of creating a trusting relationship with your child — one based on mutual respect.

How do I talk to my child about end-of-life issues?

General guidelines

- When you talk to your child, be honest and clear. Use words that your child can understand.
- Share your own ideas about death and dying. When you share with your child, you are letting him know that his feelings are OK, too.
- What you tell your child is based on his age, level of understanding, prior experience with death and your own beliefs about an afterlife.
- The most important thing you can do for your child is to be emotionally available — to be a supportive, loving, attentive adult to whom the child can come with questions or concerns.



When a loved one is dying

- If at all possible, help your child prepare for an impending death. It is much better to help your child adjust to the loss over time. Even young children will sense that something is going to happen. It may help to ease their confusion and fear if you are able to talk openly about the impending death.

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After a loved one has died

- Do not “sugarcoat” the truth. Avoid phrases such as “gone to sleep” or “passed away.” These phrases may confuse your child. For example, a child who has been told that his father has “gone to sleep” expects him to wake up.
- Most of us are confused by what we don’t understand. For children, the concept of death and what happens when someone dies can cause confusion. For example, if you tell a child that a dead person’s *body* has “gone to heaven” he may accept what you say, and yet another child will become very concerned about what has happened to the person’s *head* if, as you explained, only the *body* has gone to heaven.
- Continue to be a supportive, loving adult to whom the child can come with questions, to cry or to share memories.

How do children at different ages understand death?***Infants and toddlers (ages 0 to 2):***

Infants and toddlers really have no understanding of death. They may react to the strong emotions of adults and may be upset by a change in their routine.

Preschoolers (ages 3 to 5):

Preschoolers understand death as temporary and reversible. Children of this age have what is called “magical” thinking, and they may believe that the person who has died will come back. They may need to hear over and over that the person who has died will not return.

Preschoolers may also believe that the death is the result of something they did. For example, a preschooler may think that her angry feelings toward her mother caused her mother’s death.

School-age children (ages 6 to 10):

Most school-age children know that death is final and that every living thing dies. They are often curious about the physical details about death. School-age children may worry that death is contagious or that other people close to them will die soon.

Preteens (ages 11 to 13):

Children ages 11-13 almost always understand that death is real, final and universal. They may be interested in the biological aspects of illness and details of rituals surrounding death, such as a funeral.

Teens (ages 14 to 18):

Most teens can think more abstractly about death and its implications. Some teens may deny their mortality by taking part in risk-taking behaviors.

How do children at different ages grieve and how can I help my child?

Children, just like adults, grieve in many different ways. Often, the grief process for children is reflected by their age and level of understanding. As they grow up, they may continue to experience the loss of a loved one in new ways. Children may be sad one minute and playing the next. There may be periods when they ask many questions, and at other times they may have bouts of sadness.

This section breaks down the information by age group, first describing basics about how children grieve and then listing ideas about how to help them grieve.

Infants and toddlers (ages 0 to 2):

Very young children can sense changes in their routine and their caregiver’s emotions, so they need a consistent routine to feel safe and secure. When some infants are separated from their main caregivers, they may act differently, become fussy or have problems with feeding and sleeping. Help reassure little ones by playing with them and holding them often.

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Preschoolers (ages 3 to 5):

Preschoolers may not seem affected by the death at first because they expect the person who died to come back soon. They may have nightmares or have regressive behavior (do things that they did at a younger age, such as thumb-sucking or wetting the bed). Help preschoolers by talking about feelings so they can name some of the feelings they are having, reassure them that they did not do anything to cause the person to die, nor can they do anything to bring the person back. Also, be patient with regressive behaviors.

School-age children (ages 6 to 10):

School-age children often have a hard time expressing grief feelings. They may see death as contagious or something that you “catch,” so they worry that they will catch it or that others will catch it and die. They may be helped to understand their own feelings by hearing you talk about your feelings. They also may be helped by participating in a memorial service, although they need to understand what that is and how they are expected to behave at such a service.

Preteens (ages 11 to 13):

Preteens may worry about how daily life will change, and they may be concerned about how to mourn in public and therefore may simply withdraw socially or act out. Preteens need to be reassured that they will be cared for. Caregivers can help further by showing preteens how to express feelings, talking about them and by being good listeners.

Teens (ages 14 to 18):

For teens, their reactions may be similar to adult reactions to death. They may begin to search for answers about the meaning of life or may want to know why the person had to die. Some teens may become angry and act out, become depressed, have suicidal thoughts or escape the pain of grief by behaving in risky ways, such as using drugs or alcohol, driving dangerously or being sexually promiscuous. To help teens, offer

extra support and attention to help with the grieving process. Some teens may be willing to talk to others about their feelings and should be supported to find help from a school counselor, clergy member, social worker, private psychologist or neighborhood counseling center.

When should I seek professional help for my child?

Children show their grief in many different ways. Some children regress to behaviors that they had outgrown, such as thumb-sucking, talking like a baby or bed-wetting. Usually, this only happens for a short time and then disappears.

If your child shows any of the following symptoms, they could be warning signs that your child needs professional help. The intensity and length of the symptoms may help you decide whether or not to seek professional help. You can contact a trained professional, such as a clergy member, licensed psychologist, social worker or a member of your child’s health care team, who can help you decide whether or not the problem requires professional help or if it is a normal part of your child’s grieving process. Symptoms to watch for include:

- Suicidal thoughts or actions
- Significant changes in sleeping or eating routines
- No interest in play or other activities
- No grieving at all, no show of emotion (this should cause more concern in children over age 10)
- Increase in problem behaviors at day care or school
- Chronic misbehavior
- Physical complaints that have no explanation
- Preoccupation with death

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What can I do to help my child remember the one who has died, or how can I remember my child who has died?

There are many ways to remember a loved one. You may want to try:

- Asking the dying person to write a letter or make an audio or videotape
- Creating a memory book
- Writing a poem or story and/or drawing a picture
- Displaying a photo or creating a collage of photos
- Framing a favorite poem, saying, hymn or other item
- Making a shadow box (three-dimensional frame) that includes printed matter, photos, mementos, etc
- Planting a tree or flowering plant in memory of the person
- Putting a favorite possession or memento in a place that has meaning for your child
- Talking about the person who has died

Some faith communities celebrate the anniversary of a loved one's death.

What books might help me help my child?

Here are a few book titles that may help you, and in turn help you help your child. Check with your public library for these and other titles. A children's librarian can help you select children's books that are appropriate for your child's age:

- *The Fall of Freddie the Leaf* by Buscaglia (1982, Anniversary Edition 2002)
- *The Grieving Child: A Parent's Guide* by Fitzgerald (1992)
- *Guiding Your Child Through Grief* by Ernswiler (2000)

- *How Do We Tell the Children? A Step-by-Step Guide for Helping Children Two to Teen Cope When Someone Dies* by Schaefer and Lyons (2001)
- *When Children Grieve* by James and Friedman (2002)
- *When Dinosaurs Die: A Guide to Understanding Death* by Brown (1996)

FOR MORE INFORMATION

- Your child's health care provider
- Visit these Web sites:
 - www.kidshealth.org
 - www.seattlechildrens.org
- Read our handouts on:
 - *HIV: Children 0 to 2 years old*
 - *HIV: Children 3 to 4 years old*
 - *HIV: Children 5 to 7 years old*
 - *HIV: Children 8 to 10 years old*
 - *HIV: Children 11 to 13 years old*
 - *HIV: Teens*
 - *HIV Facts*
 - *HIV: Making Medicines Easy*
 - *HIV: Infection Control*
 - *HIV: Talking to Your Child*
 - *HIV: Talking to Your Child About Sex*
 - *HIV: Teens and Sex*

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Disclaimer: The inclusion of any Web site link (or resource accessed through a link) does not imply endorsement by Children's Hospital and Regional Medical Center. Seek the advice of your child's health care provider before you act or rely upon any information from these resources.

Children's will make this information available in alternate formats upon request. Please call Marketing Communications at (206) 987-5205.

This handout has been reviewed by clinical staff at Children's Hospital. However, your child's needs are unique. Before you act or rely upon this information, please talk with your child's health care provider.