

Caregivers Guide: Talking to Kids When Anticipating a Death

Finding out that someone has a terminal illness impacts the whole family and community, including kids. As an adult, it's okay to have your own emotions associated with the grief experience alongside a kids, and you may be dealing with identical feelings to their response to grief. With so much to process as an adult when thinking of how to talk about an impending loss, having feelings of nervousness, fear, and being overwhelmed can come up for you. However, by modeling openness and transparency you can help create opportunities for trust, allow for a kid to process their own feelings, and make them feel included in the grief journey.

Where to Start?

In talking about someone's illness figuring out where to begin is oftentimes the most difficult part. Kids are highly intuitive and can know when something is impacting them even before the conversations begin. Trust yourself and them in this process, and seek help from mental health professionals to guide you and your family through this process.



Here are some examples of how to talk with kids about death and dying with considerations on theories of child development, as well as individual strengths and cultures.

Ages 2 to 6:

Example: "[Blank] is really sick. The name of [Blank]'s sickness is called (name of illness) and the sickness is in the (part of the body) of their body. You didn't do anything to make [Blank] sick, and you can't catch the sickness from them. [Blank]'s sickness is so big that there isn't medicine to make it better. Eventually, [Blank]'s sickness will make their body die. When a person's body dies it means their heart stops working, their lungs stop breathing, and they won't be able to think or feel anything."

- Kids at this age may think the sickness is contagious. Help them understand that they will not catch the illness from the person who is dying.
- Kids can have magical thinking, meaning that they believe their thoughts can make things happen, and sometimes their thoughts are more frightening than what is actually occurring. Ensure they know they didn't cause the illness to happen.
- Kids typically don't understand the finality of death or the concept of time. Kids may ask questions repeatedly, and it can be difficult for you to keep answering them. But, continue to provide the same consistent information when you're asked repetitive questions.

Ages 7 to 11:

Example: "[Blank] has a really big sickness called (name of illness). The doctors have tried hard to figure out how to make [Blank] feel better but there is no medicine that will work. Do you know what (illness) is? (Explain illness in a developmentally appropriate way). Do you know what happens to someone's body when the medicine won't make it better? It means that someone's body dies. Do you know what it means when someone dies? It means that their heart stops working, they stop breathing, and they are not able to think or feel anything. The doctors are thinking that [Blank] has (time frame) longer to live but we don't know for sure and that is hard."

- Kids understand the concept of finality and oftentimes want more details. Consider providing specific details about the illness and how it affects the body.
- Kids understand the concept of time and may want to know when the person will die. If you know, help them understand the plan for when and where the adult will die (home, hospital, hospice, etc.).

Ages 12 and up:

Example: Discuss the illness and help the adolescent understand what the medical team has done for treatment, and how the illness is terminal. Pay attention to detail, as most adolescents seek thorough information in order to feel a part of the process.

- If appropriate, allow adolescents to attend any doctor's appointments to allow for opportunities to ask the medical team questions.
- Talk to the adolescent about when the adult is expected to die and where this will take place (home, hospital, hospice, etc.).

Ways to Support Healthy Processing During Grieving

1 Create a supportive environment with trusting adults

Find a place that feels quiet and comfortable. Consider having extra support there like a partner, or another adult who has a close relationship with the kid. It doesn't need to be the person with the illness sharing the information, but if possible have them present. Don't have too many adults involved in the conversation as it can be overwhelming. Also, consider what time of day you're having the conversation (i.e. morning vs. bedtime) and ensure there are no big events happening afterward like a sports game or test.

2 Lead with open-ended questions

Use open-ended questions during conversations to assess what a kid understands about what's going on with the illness and the person affected.

- "How do you think [blank] has been doing?"
- "What do you see happening at the doctors?"

3 Understand how much you want to share

Knowing what and how much you want to share depends on a kid's developmental age not just their physical. Below is a base of key components most kids can understand:

- Name of the illness
- If the adult has any physical changes or additional medical equipment (i.e. hair loss, oxygen tank, etc.)
- If the illness is contagious
- If the medical team anticipates the illness to progress
- The illness will end in death and there is no cure to change the end

4 Be honest and concrete with what you say

Kids can sense when adults are not being honest. Use simple and developmentally appropriate language like "death." Avoid soft language like "passed away, lost, or gone to a better place," as kids can have misconceptions about what these terms actually mean.

4 Normalize and identify kids' feelings while acknowledging your own

Kids can have confusion about their feelings, and for younger kids, they may have a difficult time identifying emotions. Help normalize feelings with validating statements such as "I understand why you feel that way; sometimes I feel that way too." Help kids to realize that they're not alone in their feelings and that other kids and even adults feel the same things when someone is very ill and dies.

5 Be prepared for different reactions and ability to process

Grief is unique for everyone and lots of factors from environment to friendships affect how kids react; and it may be in a way that you didn't anticipate after the initial conversation. Kids can only process stressful information in small amounts. After a tough conversation they might want to do something else like play, however this doesn't mean that they didn't understand. Listen, be patient, and meet them where they're at. Don't push kids to talk if they aren't ready to.

6 Give kids opportunities to ask you questions

Give space for kids to ask questions about the person's illness. Kids might not have questions right away. Encourage them to write down what they're wondering or draw pictures of what they want to ask at a later time. Let them know that you're available to talk whenever they feel like it. Sometimes, it's helpful to set up a future time to talk so kids can be prepared for when the conversation comes up again.

7 Provide reassurance, safety, and routine

Help kids understand who will take care of them and reassure them that their body is safe. Let them know those people will continue to take care of them and keep their routine as normal as possible.

8 Reflect and know your role Identity

Let kids be kids and continue being kids. Encourage them not to take on roles that the ill person can no longer do. Instead, allow kids to be involved in ways that help them still feel like a part of the person's life or family. Your role is to guide the journey by being with them to support, listen, and understand.

For more resources for caregivers visit artwithheart.org/learn

CONTRIBUTORS:

Emily Beauchemin, BS, CCLS, Helena Hillinga-Haas, MA, ATR, Lacie Braun LMHC, and Chelsey Thornton

SOURCES:

Art with Heart, "Draw It Out Leader's Companion." Seattle, WA: Art with Heart Press, 2014.

Eisma, Maarten C.; Stroebe, Margaret S.; Schut, Henk A. W.; Stroebe, Wolfgang; Boelen, Paul A.; van den Bout, Jan. "Avoidance processes mediate the relationship between rumination and symptoms of complicated grief and depression following loss. *Journal of Abnormal Psychology.*" Vol 122(4), 961-970, 2013.

Fiorini, Jody J., and Jodi Ann Mullen. "Counseling children and adolescents through grief and loss." Champaign, Ill.: Research Press, 2006.

Wolfelt, Alan D., PHD. "Healing the Bereaved Child; Grief Gardening, Growth Through Grief and Other Touchstones for Caregivers." Fort Collins, CO: Companion Press, 1996.

<https://www.cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer/dealing-with-parents-terminal-illness/how-to-explain-to-child.html>. The American Cancer Society medical and editorial content team Last Medical Review: January 14, 2015 Last Revised: March 20, 2015

 **SAFE CROSSINGS** Generously funded by Safe Crossings Foundation, safecrossingsfoundation.org



artwithheart.org