



TALKING TO KIDS ABOUT DEATH & DYING

“I don’t know how to describe it. Kinda made me really upset because, yeah everybody’s gonna die, but like my mom is gonna die, like, more than likely way before the average person. And, like, I don’t know. Like, dealing every day, like, knowing that each day she’s, like, getting worse and worse... it just... I don’t know. It makes me... upset.”

—17-year-old living with a parent who has ALS

Death, dying, loss, and grief are topics that carry taboos, confusion, mystery, fear, worry, or pain, often to the point where most of us don’t know how to talk about how it affects us, including children and youth. “Normal” life development assumes that we lose our parents when they are older, when we are adults. However, that is not the case with many conditions

Here is what the research says about talking about death and dying with children and youth:

Talking with your children and letting them express their feelings and grief helps them feel less anxious about death.

Talking helps children process the loss of someone they care about.

Children benefit from clear information in order to feel comfortable in expressing their feelings and parents are the ideal ones to start and have the conversation.

The Communication Gap: What Kids Want to Know

Children and youth often pick up on cues from their parents about whether it’s okay to discuss death. Studies, including one with youth whose parents had Huntington’s disease, show that many young people want to talk about death but hesitate because they perceive their parent as uncomfortable. This highlights a crucial point: children and youth often wait for the parent to initiate the conversation, even when they have pressing questions.

As one 16-year-old put it, "Unless she brings it [discussion of death] up, like, I'm not gonna bring it up... 'cause I don't wanna make her any sadder than she already is."

Children and youth need more than just the knowledge that their parent might die. They want details to help them process and cope. Be prepared to answer questions like:

- What will the death look like?
- How will it be handled? Will the parent remain at home?
- Can the child be present during the death?
- What will happen to the child after the parent dies?
- What will the funeral or services be like?
- What support systems will be in place?
- Where will the family live after the parent dies?

The Communication Gap: What Kids Want to Know

Opening and maintaining these conversations is vital. While the specifics will vary based on a child's age and maturity, honesty is paramount, even if you don't have all the answers. It's okay to admit you're unsure or that the topic is upsetting for you, too. Let them know you'll work together as a family to find answers and address these difficult realities.

Preparing for End-of-Life Decisions

Children and youth often don't understand end-of-life decisions. It's important to explain why certain choices are being made, such as opting to forgo treatment or bringing in hospice care. Clearly communicate who will be in the home and what changes to expect. Shielding children from these realities can cause more confusion and distress than preparing them for what's to come.

Tailoring Conversations to Your Child's Age

Talking to children about illness, loss, and death is never easy, and there's no one-size-fits-all approach. How children understand and cope with these difficult topics varies significantly by their age and developmental stage. What's appropriate for a preschooler will be very different from what a teenager needs to hear. This section offers guidance on how to adapt these sensitive conversations to meet your child exactly where they are, helping them process complex emotions and information in a way that makes sense to them.

How Do I Talk to My Kids Who Are at Different Ages?

DEVELOPMENTAL STAGE	POSSIBLE REACTIONS	SUGGESTIONS FOR TALKING WITH THEM
Infants and Toddlers (Age 0–3)	Fussiness, irritability Clinginess Tears, vomiting, regression in behavior such as toileting, sleeping, or eating	Maintain a regular routine. Provide nurturance and physical security, such as holding and cuddling with child. Provide reassurance and patience. Allow child to play, as this is an outlet for children’s grief.
Preschoolers (Age 3–5)	Numerous, repetitive questions; curiosity about death May appear unconcerned or show little reaction. Regression in behavior such as nightmares, toileting, possible violent play Fear of separation	Allow questions and talk with child. Answer questions honestly and in simple words and terms. Use real terms, such as death or dead, not “sleeping” or “gone away.” Provide structure and a normal schedule. Offer patience, explanations, and assurance. Resist punishment for acting out. Encourage physical activity and play to express feelings and expend energy. You may have to clarify that death is not contagious.
Young Children (Age 6–9)	May want details and explanations about death. Crying; active mourning Will be concerned about others’ feelings. Grief expression may come and go. May appear anxious or emotional; may “act out”	Provide reassurance. Respond to their needs and questions honestly and compassionately. Allow for creative play through art, stories, etc. Encourage physical play as an outlet for grief and energy expression.

Middle Childhood
(Age 10–12)

Distractedness, denial, guilt, anger School work may suffer; grades may fall. May fear leaving home or parents; separation anxiety May put on a “brave face” and not show emotions. May withdraw or act out

Give permission for expression of feelings. Encourage child to ask questions and give honest answers. Avoid punishment, but offer encouragement, reassurance, compassion. Allow child to NOT be brave by giving them time to express emotions and worries. Ask if and how the child might like to be involved in the memorial services. Remember to give hugs.

Adolescents
(Age 13–19)

Crying, traditional mourning Denial or risk taking Taking on the adult role; being the “man” or “lady” of the house Depression; suicidal thoughts Willingness to talk with peers or non-family members about the death Change in behavior at school; grades falling

Encourage conversation and expression of grief; be honest. Allow child to have time to mourn; do not expect them to take over the adult role. Seek out professional help, if needed, such as a school counselor, professional therapist, or clergy. Utilize teen support group services. Provide love and support.



The mission of Global Neuro YCare is to EDUCATE through the creation and translation of materials and programs for children, youth and families; ADVOCATE with national and international organizations to guide the creation of regional, cultural and country-specific programming; and SUPPORT research addressing the needs and experiences of young carers.