Grief Support for Children with Intellectual and Neurodevelopmental Disabilities

Like all children, children with intellectual and neurodevelopmental disabilities may experience the death of a loved one. These children often face distinctive challenges at such moments. Educators and providers play a vital role when they talk with children about grief. While every child is unique in the way they grieve, virtually all children will appreciate support and understanding. Adults familiar with the communication style of children with intellectual and neurodevelopmental disabilities have a unique opportunity to engage in these exchanges and conversations.

Here are some points to keep in mind.

GRIEF BEHAVIORS

Children who cannot communicate well verbally will generally express their feelings in non-verbal ways. When grieving, they may show a range of behaviors in response to stress and emotion, including a reappearance of challenging behaviors that they demonstrated in the past or greater intensity in current ones. They may be more irritable or angry than usual. They might lose weight. They may sometimes regress to earlier behaviors—being clingy with caregivers or bedwetting, for example.

They may begin or increase self-stimulating behaviors such as pacing, flapping arms or repeating a word or phrase. They might rock, chew on clothes or fingers, or want lots of bathroom breaks during class. They might exhibit disruptive behavior, difficulty concentrating, or want more explanations than usual. They may express their grief through idiosyncratic rituals or other unusual behaviors that are misinterpreted by others.

OFFER EXPLANATIONS MATCHED TO THEIR LEVEL

It is important for any grieving child to understand <u>four concepts</u> <u>about death</u> (see box). Talk about these concepts in ways that match a child's developmental level. Follow-up with questions that can highlight any misunderstandings.

Four Concepts About Death

- 1. Death is irreversible.
- 2. All life functions end completely at the time of death.
- 3. Everything that is alive eventually dies.
- 4. There are physical reasons someone dies.

For example, if you were explaining concept #2 to a child with a developmental age around five years, you might say, "When

1-877-53-NCSCB (1-877-536-2722) www.schoolcrisiscenter.org people die, their body stops working forever. They can't see or hear, move or feel pain. They aren't hungry or scared." If the child then talks about their grandfather's funeral, you might ask, "What was it like for you when your grandpa was being buried?" If the child replies they thought their grandpa was probably scared, reassure the child again that once someone has died, they no longer feel pain or fear.

THE CHALLENGE OF GRIEF FOR CHILDREN WITH ASD

Children with autism spectrum disorder (ASD) or other neurodevelopmental differences have distinct styles of social interaction. While these children may not be able to verbalize their feelings or ask for support as clearly as other children, they do experience grief.

You may be familiar with some common stressors for children with ASD. These include unexpected events, disruptions in routine, changes in the behaviors of family or peers, powerful emotions, trying to communicate thoughts and feelings, and facing new sensory processing demands.

The death of someone close brings challenges in every one of these realms. A loved one is gone. Visitors show up in the home. There may be new people at the dinner table, a memorial service to attend, or new and confusing emotions to manage.

In addition to the actual loss of the loved one, grieving children experience a range of <u>secondary losses</u> that resonate powerfully for those with ASD. Their routines are likely to be disrupted, perhaps temporarily, but sometimes permanently. There may be a change in family finances, home location, school and social connections. A parent or sibling who has been a vital support may still be alive yet be distracted and less available due to their own grief feelings.

Educators can provide valuable consistency during this time by putting strategies to work that have been effective with the child in other areas, focusing on issues related to grief. Tell a social story about someone who has experienced the death of a pet or family member. Ask a child to demonstrate body language that expresses sadness. Consider using drawing or other techniques to help children express their feelings in other ways. Talk about ideas for regulating the strong emotions that come up while grieving. Validate appropriate feelings that children express such as sadness and reassure children that these difficult feelings are common for all people who are grieving, not just for those with ASD.



