Dougy Center: The National Grief Center for Children & Families

Supporting Children & Teens with Autism Who are Grieving

This resource is a collaboration with Jennifer Wiles, Director of HEART*play*. Jennifer is a Licensed Mental Health Counselor, a Board Certified Dance/ Movement Therapist, and a Fellow in Thanatology. Since 1995, HEART*play* has provided grief support to families in the Boston area. Their current focus is on serving individuals with disabilities and working to provide programming that is accessible to participants of all abilities.

This resource is rooted in a Grief Out Loud podcast interview with Jennifer, who joined our host, Jana DeCristofaro to discuss ways parents, caregivers, and other community members can provide concrete, compassionate, and creative support for children and teens with autism who are grieving.

A note about language: In both our conversation with Jennifer and this collaborative resource, we use person-first language — "children and teens with autism." We also recognize that language preferences vary, and some individuals and families may choose identity-first language, such as "autistic child" or "autistic teen." The most respectful approach is to ask each person or family what language they prefer and follow their lead.

Dougy Center: What suggestions do you have for parents and caregivers for how to tell children and teens with autism that someone in their life has died?

Jennifer: I would say it's the same advice we as bereavement professionals give all the time, which is: be honest, be concrete, be specific. Don't use euphemisms like: *He's gone*, *We've lost him*, *She's asleep*, *They went on a long trip*, *She's up in the stars*, *etc*. We've all heard these, but they just create more confusion, especially for concrete thinkers.

Families might use a visual support to talk concretely about what death means. For instance, explain that the body is no longer working, the heart no longer beats, and this person will not talk, walk, eat, or breathe again, and we will not see them alive again. I know that sounds very blunt and almost harsh, but by being definite and concrete, it helps children start to understand and be able to ask questions.

It's also important to let children and teens know what to expect emotionally. Things like: *I am going to be sad; People will be sad; That means you might see me crying; It means our routines might change, like we might be busy and not eat dinner at six o'clock tonight.* I think that's a good place to start.

Note: While euphemisms can be confusing for concrete thinkers, it's important for families to use language that is culturally relevant for them. If a term such as *passed away*, *transitioned*, *no longer with us*, or another way of describing death best reflects your family's culture or beliefs, it's helpful to also explain what that term or phrase means using the concrete language suggested above.

Dougy Center: What are the most common misperceptions or misunderstandings around how kids and teens with autism respond to grief, especially grief from a death loss?

> Many families of children with autism have already experienced non-death losses (missed milestones, isolation from peers, inaccessible community events). The death of a person — or a service animal — can layer on top of existing grief.

Jennifer: I think the most common misconception is that these kids are not grieving or that they don't care. If they aren't showing outward emotion, people might think they are oblivious to the fact that there has been a death. Or, if they are responding strongly, some might think that it's not because of the death, but because of their intolerance for the topic. I think it can take these kids a while to fully understand the concept of death, what happened, how to process, and then to express it, but that doesn't mean they don't care.

The other piece is that some kids and teens may have strong reactions to how the death creates a change in their schedule or routine, and those reactions can be misinterpreted as a sign that they don't care about the loss.

Common misconceptions about grief and autism

- People often assume that if a child with autism doesn't express grief "typically," they aren't grieving.
- Grief may look like a shift in behaviors (e.g., increased stimming, meltdowns, shutdowns, or agitation) rather than crying or verbal expression.
- Sensitivity to routine changes may be misinterpreted as a lack of caring about the death, when it's often both grief and distress about disruption.

Dougy Center: From your experience, what other ways do children and teens with autism express grief that might stand out to others as different, confusing, or hard to read?

Jennifer: I think about how a family might suddenly be in the public eye with people in and out of their home or at events to honor and memorialize the person who died. Some children with autism have a very low tolerance for these events that can have many sensory changes like noise, smells, different foods, and a lot of new people who might want to hug and talk to them. These experiences can be very dysregulating for these children.

Grief may look like:

- Repetitive questions ("Where is Dad?" over and over)
- Changes in behavior or mood
- Increased reliance on self-soothing strategies (rocking, flapping, intense focus on a subject)

*These are **coping skills**, not signs of disinterest or regression*

Dougy Center: How can families support children with events like funerals, memorials, and other public gatherings to honor the person who died?

Jennifer: It's important to be clear about what a child or teen can expect to happen at these events and prepare them for situations that could be hard to make sense of as concrete thinkers. Social narratives can be very helpful as they break these situations down into simple parts and help a child anticipate what might happen.

A great example is at a wake, Shiva, or other gathering where people tell stories about the person who died. As people talk more, maybe they're laughing and kind of joking and remembering something happy. That laughter and smiling can be very confusing to a concrete thinker. "Why are these people laughing and joking? This

Tips for memorials and other gatherings

- Use visual supports and social narratives to help prepare children for what to expect.
- Include sensory details: crowds, hugs, smells, sounds, and what people might say.
- Identify a trusted support person who can accompany the child or help them leave the space if needed.
- Collaborate with funeral homes ahead of time to arrange a quiet room or comfort materials (e.g., headphones, fidgets).

is supposed to be sad." So, it's helpful to explain that people can be sad and still smile, tell jokes, and laugh.

Another piece is to prepare kids for the things people might say like, "I'm sorry for your loss," which can also be confusing. We can help by giving children options for how to respond, whether with a hand signal or words.

Dougy Center: What suggestions do you have for parents and caregivers in supporting kids and teens with significant days such as anniversaries of a diagnosis or death, birthdays, and holidays?

Jennifer: This is a question that comes up for almost every family. I think it's important to discuss and come up with a plan, even if you decide on that day to scrap the whole idea. Specifically for kids with autism, it's good to keep it very short, uncomplicated, and manageable.

> Supporting a child or teen with autism who is grieving requires **patience, attunement, and creativity.** Grief might look different—but it is no less real. Honoring all ways of communicating and connecting is essential to compassionate grief support.

It could be something as simple as lighting a candle together as a family. Other ideas I've heard from families include throwing a stone into the water, saying the person's name out loud or writing it on a special piece of paper, looking at a photo, or reading a favorite book.

It's important to acknowledge the day, but again, keep it simple and something that everyone can participate in.

Dougy Center: For the parents and caregivers you work with, what have they learned from supporting their child or teen that has helped them in their own grief?

Jennifer: I think the parent or caregiver is often compelled to name their own emotions and experiences, in a very concrete way, in order to communicate that with their child. There's a process that many parents go through, wondering, *How much do I keep inside? How much do I show my child that I am upset, that I am grieving, that I'm uncertain, scared, lonely, afraid, anxious, etc?* Or, *How much do I shield them from the emotions I'm feeling?* It compels parents to get down to the core of what they're feeling, to learn to label their emotions, and to break them down in a way that their child will understand, such as communicating something as simple as, "I'm feeling sad today." An example is a parent who says, "I miss

Non-verbal grief support strategies

- Use movement, rhythm, and sensory memory to support emotional expression:
- Create dances or gestures based on sensory memories (e.g., smells, sounds, sights tied to the person who died)
- Drum or rock together for soothing rhythmic connection
- Mirror a child's movements as a form of attuned support

*Recognize and advocate for these as **valid languages of grief**.*

mommy, so you might see the sad look on my face, you might see a tear in my eye. That means I'm sad and I miss mommy." Again, getting to the core of their experience and communicating that in a concrete way to their child often helps them lean into those hard feelings and that pain in a way that shows the child, *I am here for you, and I am human at the same time.*

ADDITIONAL RESOURCES

Books:

- *I Have a Question About Death* (Meredith Polsky & Arlen Gaines)
- *Understanding Death and Illness and What They Teach About Life* (Catherine Faherty)

Activity suggestions

- **Create a visual support:** Use clear visuals and simple text to explain the death, funeral, or changes in routine.
- **Movement Memory Ritual:** Help the child create a series of gestures based on sensory memories of the person.
- **Emotion Labeling Practice:** Use visuals or body language to help children identify and express feelings.

HEART*play* Program:

- Free downloadable social stories and grief support tools at heartplayprogram.org

Grief Out Loud Podcast Episodes:

- Ep. 20 Grief & Developmental Disabilities
- Ep. 289 Autism & Grief
- Ep. 321 Building A Relationship After Someone Dies

National Alliance for Children's Grief Toolkit:

- "Supporting Children of All Abilities Who Are Grieving," nacg.org

Carol Gray, Social Stories™:

- carolgraysocialstories.com

HEART*play* is a heart-centered bereavement program. Our mission is to support children, teens and young adults of all abilities and their families who are coping with the serious illness or death of an important person in their lives.

heartplayprogram.org • 508-309-5107

The mission of Dougy Center is to provide grief support in a safe place where children, teens, young adults, and their families can share their experiences before and after a death. We provide support and training locally, nationally, and internationally to individuals and organizations seeking to assist children who are grieving.

dougy.org • help@dougy.org • 503-775-5683