How to Talk With Children With Autism About Death and Grief

When Benay Josselson's husband, Steven, died suddenly at age 39, she knew she was entering uncharted territory. In the midst of dealing with her own devastating loss, she needed to help her young children, ages five and eight at the time, process the death of their father. Making matters more complicated, the older of the two boys has autism, and Josselson quickly realized that the traditional methods of understanding death and dying were not compatible with how her son processes.

Many children's books approach the topic metaphorically, using animals or objects in nature to provide a gentle way of introducing the topic of death and dying. For many children with autism spectrum disorder (ASD), understanding these metaphors is extremely difficult. These types of books in which the reader is required to make the leap from animals to people are simply not accessible for many children with autism.

So how can parents and caregivers help our children grapple with topics as challenging as death and grief?

First and foremost, take a moment and recognize that everything you do to support your child on the autism spectrum every day can be extrapolated to guide them through the death of a loved one and the grief that may follow. Think about how you prepare your child for any change in routine, new experience, understanding others' emotions, sensory challenges and their own personal feelings. All of these strategies are relevant as you help them navigate death and grief.

Second, just as animals and objects in nature are challenging metaphors for children on the autism spectrum, so too can abstract ideas like "passed away," "gone," "sleeping" or "better place" provoke anxiety and confusion. When talking about someone who is dying or has died, use the real words. While

"dying" or "died" may feel harsher to an adult, children will feel less puzzled and scared not having to "guess" at what you are trying to tell them.

In cases where it is possible to anticipate the loss (as opposed to a sudden death), it can be helpful to talk with the child as it is happening as a way to prepare for the eventuality of death. Using language that is open, honest and concrete can go a long way in helping a child with special needs navigate this complex issue.

Third, anticipate the practical changes in routine that happen after a death, and utilize previously helpful strategies as you support your child during this time. For instance, if the child will be attending a funeral or memorial service, you can write a checklist with the day's schedule and have the child check off activities as the day goes on: get dressed up, drive to the funeral service, sit at the funeral, drive to the cemetery, etc. It can also be helpful to verbally prepare the child or draw simple pictures about what they might see and experience at each step in the process. Have a trusted adult available to be with the child during a funeral in case a break is needed, and have comforting items on hand such as a favorite toy, fidget, or stuffed animal.

Lastly, consider the emotional and sensory challenges that may emerge after someone has died. Since some children on the autism spectrum may have difficulty reading the emotions and social cues of others, try preparing the child for the range of emotions they might see: People cry as a way to express their sadness about the death, and laugh when sharing a funny memory. Let the child know that people might want to give them hugs as a way to offer comfort, and try to make a plan with your child so they can take a break. These discussions and preparations may also help the child better identify and understand his/her own feelings.

As you continue to support the child, help them remember the person who died in ways that are meaningful and accessible. For example, if the aunt who died often traveled by train to come visit, you

can help make a connection between that and the child's love of trains. As a caregiver, keep in mind that your child may regress or turn to self-soothing behaviors during this time. Be prepared to answer questions and offer the kind of support that works for the child, such as quiet time, playing outside, or other preferred activities. Remember to utilize your whole team, and inform teachers, therapists, and counselors of the death so they can work with you in supporting the child during this challenging time.

Helping any child navigate the death of a loved one can be daunting, but may be particularly so when the child has ASD or other special needs. As Benay and so many others have discovered, though, when done in a way that takes into account the child's specific developmental, social, and learning needs, a discussion such as this can be not only meaningful but can serve as an important foundation as the child grows.

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