

# PATHWAYS CENTER *for* GRIEF & LOSS

## **BEREAVED INDIVIDUALS WITH AUTISM**

Each person's grief process is unique, and this holds true for all individuals with Autism. Autism is a spectrum, and each individual may express their grief emotions in a variety of ways. While their grief may present differently with people who don't have Autism, it is not non-existent. Individuals with Autism may regress or attempt to isolate themselves due to overstimulation and increased anxiety surrounding the increased emotions. It is important to recognize they may also struggle with inability to verbally process their grief emotions with others.

Individuals with Autism may be focused on the loss of relationship and the loss in routines associated with that person rather than the emotions surrounding the death of the actual person. Grief may cause stimming (self-stimulating) behaviors and increased emotional outbursts. Increased anxiety surrounding the individual, close family members and friends may also be present. Honesty is critical. When details are left out, processing the death may take longer, as it does not make sense because they can be so literal.

### **THE NEED FOR PREPARATION & REPETITION**

Individuals with Autism are likely to require frequent explanations to grasp ideas. Do not assume that once you've explained about the death, they will therefore understand the next time it comes up. Frequent review and repetition is needed. Role-playing, art activities, social stories, and teachable moments about the cycle of life and death are invaluable tools to use since they may have difficulty conceptualizing life without their loved one. For example, although you may have explained in great detail what to expect at a funeral or service, it is best to walk through the events of the day prior to the service itself in the funeral space. This will allow the person with Autism the opportunity to understand your explanations, ask questions, and feel more prepared before dealing with the added emotion that occurs at the time of the actual service when a lot of people are around. It is also important to explain that people will express their emotions surrounding the death in a variety of ways. There will be sadness, crying, and in some instances laughter or smiling. This is especially likely if there is a meal or family gathering after the service.

Individuals with Autism often see the world from an egocentric or singularly focused viewpoint. When a death occurs, they may be more likely to assume that they are to blame, or that they in some way caused the death. Magical thinking and perseveration may be present. They will pick up on the intensity of the emotions around them regardless of what they have been told, so it is not wise to withhold information. They will fill in the blanks regarding what they haven't been told and often their thoughts are worse than the reality.

### **ADDRESSING BEHAVIORAL PROBLEMS**

Acting out behaviors are common. It is important to remember that these are in response to the grief and should therefore be viewed as clues to emotions. Look for ways to draw out these hidden issues. While modifying the behavior, also explore the feelings that may be causing the acting out behavior. Remember that "grief expressed is grief diminished."

*(over)*

## STRATEGIES

- Provide a safe place...
  - to ask questions
  - to mourn (express their reactions to loss)
- Use teachable moments when possible
- Routines are helpful...
  - they promote security
  - and predictability
- Look for the question behind the question
- Draw from your own experiences and examples
- Encourage expression of feelings and memories with any interventions listed which may be appropriate

## INTERVENTIONS

- Don't avoid talking about it. Explain it as fully as possible. The individual's misinterpretation might be worse than reality.
- Use social stories\* to describe the funeral or services
- Look for everyday examples - explain that death is part of the natural cycle of life. Use examples as simple as finding a dead fly on your windowsill, or the death of a famous person that you read about in the newspaper.
- Use death as a concrete term
- Avoid euphemisms - Terms like, "going to sleep", or "passing away" can be confusing for someone who interprets language literally.
- If your belief system includes Heaven, help the child understand that Heaven is not a place that you can simply visit. Otherwise, the child might become frustrated that his/her loved one is simply in a different place, but not communicating or visiting.
- When possible, include them in the funeral process. Providing the concrete experience that will help them understand.
- Try to keep other aspects of life as consistent as possible
- Provide as many opportunities for structured choice as possible.

Individuals with Autism Spectrum Disorder often struggle when their anticipated routines change. As soon as possible, try to resume normal activities. This will help decrease apprehensions that compound grief.

## ADDITIONAL RESOURCES:

- *\*A Sample Social Story for Death and Grieving* - <https://www.pathfindersforautism.org/wp-content/uploads/2017/01/social-story-about-death-and-grieving.pdf>
- *Gray's Guide to Loss, Learning, and Children with ASD* by Carol Gray - <https://carolgraysocialstories.com/wp-content/uploads/2015/10/Spring-2003-ISSUE.pdf>
- *How People With Autism Grieve, and How to Help: An Insider Handbook* by Deborah Lipsky
- *Understanding Death and Illness and What They Teach about Life: An Interactive Guide for Individuals with Autism or Asperger's and their Loved Ones* by Catherine Fahert



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