BEREAVED INDIVIDUALS WITH INTELLECTUAL DISABILITIES OR DEVELOPMENTAL DELAYS

Bereaved individuals with intellectual disabilities or developmental delays are a unique population. Grief for individuals with intellectual disabilities or developmental delays may take longer to work through. This is due to their cognitive functioning, their potential need to have information repeated many times, and the possibility of their life-long dependency attachments. Simple honest explanations, as well as a clear intention to include the individual in the process as much as possible is the most effective way to provide these individuals grief support after a death.

Philosophical discussions of death have little meaning. Concrete examples are a necessity. Teachable moments and applications to daily life are the most helpful way to reinforce the concepts. These literal experiences will deepen their understanding. *Lifetimes* by Mellonie and Ingpen, *The Dead Bird* by Margaret Brown, *It Must HURT A Lot* by Doris Sanford are excellent books to help the concepts become more concrete and understandable.

**The Need for Repetition:**

Individuals with intellectual disabilities or developmental delays are likely to forget what is taught and require frequent explanations to grasp the ideas. Don’t assume that once you’ve explained the death, or even once they’ve experienced a loss, they will therefore understand the next time. Frequent review and repetition is needed. Role-playing, interactive activities, and teachable moments about the cycle of life and death are invaluable tools to use because they have difficulty generalizing to new situations. For example, although you may have explained in great detail what to expect at a viewing at the funeral home, it may be wise to arrange for a private showing before the public one. This will allow the person with intellectual disabilities or developmental delays a chance to clarify what was understood, ask questions and feel more fully prepared before dealing with the added emotion that occurs at the time of the actual viewing when a lot of people are around.

Individuals with intellectual disabilities or developmental delays often see the world from an egocentric viewpoint, so when a death occurs they may be more likely to assume that they are to blame. Listen for magical thinking. They will also 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 and imaginations are worse than the reality.

**Addressing Behavioral Problems:**

Acting out behaviors are common. It is important to remember that these are a response to the grief and should therefore be viewed as clues to emotions. Deeply troubling thoughts, concerns or fears may be underlying the feelings and behaviors, and these can be quite persistent. 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. As a caregiver, your role is to facilitate the grief process and appropriate means of expressing feelings. Remember that “grief expressed is grief diminished.”

**STRATEGIES**

- Provide a safe place... to ask questions to mourn
- Use teachable moments throughout the year
- Routines are helpful... they promote security and predictability
- Look for the question behind the question
- Draw from your own experiences and examples
- Provide hope for healing
- Encourage expression of feelings and memories with any interventions listed which may be appropriate

**INTERVENTIONS**

- Art Activities
  - Drawing
  - Clay Modeling
  - Painting
  - Collages
  - Body Tracing
- Puppet Activities
- Memorials
  - Memory Book
  - Memory Box
  - Photo Album
  - Scrap Book
  - Ornaments
- Writing Activities
  - Journaling
  - Letters
  - Sentence Completions
  - Poems
  - Acrostics
  - Lists
- Story Activities
  - Books
  - Storycards

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