Andrew Roth has had his share of encounters with death. From the time he was eight years old, several people close to him have died: his brother, two grandparents, an uncle, an aunt and a dear friend of his mother’s. He has gone to their funerals and his parents have talked to him about each loss. But what this now 28-year-old man with autism truly understands of death in general, and the loss of his loved ones specifically, his mother cannot say.

“A lot of our kids are nonverbal and don’t understand what a loss means,” says Elizabeth Roth. Nevertheless, she doesn’t discount the possibility that Andrew understands more than one would think. “We don’t know if [people with autism] really do understand, even if we think they do not.” She cites Andrew’s passion for game shows as an example. “My son, who doesn’t really have a lot of school knowledge, answers questions on his favorite game shows.”

In fact, it is Andrew’s beloved game shows that reveal to some extent his comprehension and handling of death. He is enthralled by the game show hosts he sees on television, as well as radio and television newscasters. He keeps close tabs on their career statistics, which he meticulously logs into his computer.

“When they die, it is very important to him,” Roth says. “He re–does his list on the computer to catalogue the person’s death.” Andrew has “volumes and volumes” of information about these celebrities, “and he is constantly looking up who died.”

This fixation about death doesn’t extend to friends or family members, however. Although his mother believes Andrew makes the connection that in death both the celebrities and people he personally knew are gone forever, the two do not merit the same level of attention.

BREAKING THE NEWS

Roth says she and her husband John always tell Andrew of a relative’s or friend’s passing so that he doesn’t anticipate seeing them again. In language that is clear and literal, “you have to try to tell [people with autism] that the person is gone and won’t come back,” she advises.

Andrew’s parents tell him that the loved one has joined other friends and relatives who have died. She notes the importance of emphasizing...
Roth and her son Andrew

The matter of who delivers the news is an important factor to consider in some instances, depending on the person with autism and their level of comprehension, according to Roth. However, this is not the case for Andrew. “For Andrew, it’s just a fact,” Roth says.

She adds that for some, a religious context is appropriate, while for others it may not be. “I tell my son that they [the deceased] are going to live with God. Does Andrew understand God and heaven? Maybe. Maybe not. He does pray. He doesn’t know very many prayers, but he does it anyway.”

Roth cautions, however, that anyone sharing such news with a person who has autism should be mindful of their surroundings. Andrew’s reaction to the news of death is to laugh, a reaction not uncommon to people with autism. Whether it’s a stress reflex or simply an involuntary response is unknown, but the misunderstood inappropriateness could be offensive to some.

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Help the person with a developmental disability recognize and accept his/her feelings.
Lavin explains that death can trigger buried emotions related to previous losses, abandonment, fears and guilt. People with developmental disabilities should be allowed to discuss their experiences of grief in a “safe, patient environment.” Expressive therapies, such as art and music, also can help people who have trouble expressing their grief verbally.

Help the person accept the reality of the death. Lavin stresses the importance of telling people with developmental disabilities the truth about a death. Otherwise, they are likely to create their own version of the “facts,” she cautions. Clarity in explanation is crucial, and Lavin discourages using euphemisms. For example, instead of saying, “He is living with God,” it is clearer to say, “He is dead.” People with developmental disabilities also should be allowed to take part in the process as much as possible.

Participation in rituals helps people cope with loss (Doka, 1989). People with developmental disabilities should not be denied the opportunity to say good-bye. Lavin cites as an example offering a memorial service at the group home so that residents can express their feelings in a community.

How to Help Ease the Grieving Process for People with Developmental Disabilities

In a book edited by Kenneth Doka and Joyce Davidson, Living with Grief: Who We Are, How We Grieve (Hospice Foundation of America), Claire Lavin, Ph.D., offers a number of suggestions to help people with developmental disabilities cope with grief. The following is an excerpt from the chapter, “Helping Individuals with Developmental Disabilities.” Lavin is a professor of psychology at the College of New Rochelle (N.Y.), and a clinical and school psychologist. The full text of Lavin’s writing is available online at the Hospice Foundation of America’s Web site: www.hospicefoundation.org/teleconference/books/lwg1998/lavin.pdf.
SHARING THE EXPERIENCE

Roth says it also is important for people with autism to be included in the family’s activities related to the death so that they can come to terms with its finality. “We always make sure Andrew goes to the funeral home so that he can see [that the person] has gone away and he won’t be seeing them again,” she explains. That’s not to say there haven’t been surprises.

Roth says that when Andrew was at his grandmother’s funeral, he announced, “It’s time to go, Grandma,” and tried to take her out of the casket to take her home. “We [have] to remind him each time that you cannot take the person with you,” she says.

Aside from his concern over leaving his loved one in the funeral home, Andrew shows no emotion over the event. When his parents tell him of a death, his initial response is to giggle, and then he repeats the news back to his parents. “And that’s it,” Roth says.

In fact, Andrew has been far less tolerant of another type of loss, that of people leaving him due to travel or a change in circumstances. At the start of a new school year or when switching classrooms, Andrew and his friends would refuse to acknowledge their previous teacher. “The old teacher would be dead to them,” Roth says. In fact, Andrew still holds a grudge against a formerly favored teacher he “lost” some seven years ago.

Andrew did the same thing to his mother when he was around 7 years old and Roth, who currently is on the Autism Society of America Board of Directors and is co-president of the Montgomery County, Maryland, chapter, would travel to ASA conferences. “When I came home, he’d have nothing to do with me,” she recalls. Two or three days later, Andrew would let his disapproval be known by pouring shampoo on the carpet or by way

Using pictures and videotapes to recall the person provides a forum in which people can discuss relationships, share feelings and recall good memories. This also reinforces the fact that memories remain, even though the person is gone.

Religion provides strong support for many in times of loss. “People with developmental disabilities should be encouraged to explore their spiritual beliefs and utilize their religious rituals,” Lavin states.

Acknowledge the fact that people with disabilities may express grief nonverbally, including by using disruptive or disturbing behavior. Lavin suggests responding with empathy rather than becoming annoyed, and to name the feelings behind the behavior: “You are angry because John died, and so you won’t eat. You feel angry, angry, angry. And that’s okay.”

Be alert for grief reactions requiring psychiatric intervention. Lavin cautions that behaviors often are incorrectly attributed to the primary disability rather than to the depression that requires intervention.

Provide the support that now is missing from the person’s life. Lavin tells of one man with cerebral palsy who for many years had depended on his brother for company and transportation to a favorite restaurant. This event was one of the high points of his life. When his brother died, the man no longer had this essential outing available to him.

Be an advocate for the person to allow him/her to mourn and participate in rituals, if others fail to recognize his/her need to do so.

Reference

of some other damaging gesture. “It was like he was getting back at me for deserting him,” Roth says.

**DIFFERENT KINDS OF LOSS**

Roth says Andrew does draw a distinction between loss due to death and loss due to travel or change. He recognizes that while those who have died are gone, those who “left” him are still around. And, interestingly, while he painstakingly catalogues the deaths of game show hosts and newscasters, he does not record the deaths of family and friends. His reaction of laughing, however, is the same for both.

Roth believes Andrew also has some concept of death as it relates to himself, due to his parents’ efforts to emphasize the dangers of traffic and crossing the street. When Andrew was a teenager, he was nearly hit by a speeding tractor trailer, but was completely oblivious to the harrowing incident. Since then, his parents have employed a number of creative methods to convey their message about vehicular hazards.

One tool was to show him illustrative cards depicting a person getting hit by a car, being taken by ambulance to the hospital and leaving the hospital. He was also shown a card illustrating that the person had died. To underscore the point, the Roths also showed Andrew a tape that police departments use to warn teenagers about the gruesome road-wreck perils of drunk driving.

But the most effective visual turned out to be the dead deer hit by cars that they saw on the roadways. “The dead deer made an impression,” Roth says. It took more than a year for Andrew to make the connection, but now when his mother points to a dead deer in the road, Andrew says, “Dead deer. No die (meaning himself).”

“Since he’s seen the deer, he has a fear of death,” she says. “He understands dying means you’re gone.”

About the Author

**SHARY DENES** is a freelance writer in Sugar Loaf, N.Y.