COPING WITH DEATH

Coping with death can be particularly difficult for individuals with Autism Spectrum Disorder (ASD) for many reasons. First, it means change and loss. Second, death is fraught with emotion, and the adults helping the child learn what death is all about are usually the same adults coping and dealing with their own loss and sadness, making them not as emotionally available to help the individual with ASD. Third, death is abstract and intangible. It is not something one can see or touch. It makes it very difficult to explain to someone with ASD. Additionally, death comes with ceremony and ritual which incur changes in routine and scheduling. Guests arrive, or the family travels from home. This change in routine and expectations can be devastating.

Explaining all of this can be difficult at any time, but even more so when one is already upset. Expect the individual with ASD to react to all that is going on around him or her. Behaviors may be more extreme and reactions not appropriate. When learning about a death, the individual with ASD might laugh, cry, or clap hands. The reaction is difficult to predict and should not be taken as an accurate reflection of the individual’s feelings.

What can you do?

If a loved one becomes ill, it is best to talk to the individual with ASD about the illness, possible hospitalization, etc. These discussions can be preparation for dealing with the healing, the transition to moving the individual to a rehabilitation facility, or even death.

As with explaining anything to an individual with ASD, be as clear, as precise, and as factual as possible. The message should be consistent among all who speak to the individual with ASD. Mixed messages will cause confusion and anxiety. Saying the person who died “Went to sleep” is not a good idea, because it is not true, and may cause the child worry about going to sleep.

There are other things to consider as well, including whether the individual with ASD should attend the funeral or memorial service or who the individual might be left with if not attending.
Consider enlisting the help and support of a counselor, teachers, or other support staff who know your person with ASD well.

Information and books for typical children about death may help support the entire family. Sometimes a child with ASD can benefit from a book written for a younger child.

Related Articles:

- LIFE CYCLE EVENTS
- SOCIAL STORIES RELATED TO ILLNESS OR DEATH

Additional Resources:

- HOW TO TALK TO CHILDREN WITH AUTISM ABOUT DEATH
- DEATH, BEREAVEMENT AND AUTISM SPECTRUM DISORDERS
- BEREAVEMENT AND GRIEF RESOURCES, FROM AUTISM SPEAKS®

Additional Reading:

- *I Miss You: A First Look at Death*, by Pat Thomas
- *Help Me Say Goodbye: Activities for Helping Kids Cope*
When a Special Person Dies, by Janis Silverman

When Children Grieve by John W. James and Russell Friedman

The Center for Autism Research and The Children’s Hospital of Philadelphia do not endorse or recommend any specific person or organization or form of treatment. The information included within the CAR Autism Roadmap™ and CAR Resource Directory™ should not be considered medical advice and should serve only as a guide to resources publicly and privately available. Choosing a treatment, course of action, and/or a resource is a personal decision, which should take into account each individual’s and family’s particular circumstances.