

STAR Information Series: Understanding Death

How can we help people with autism after the death of someone close to them?

If possible, a person with autism needs to experience rituals and grieving with people who love them. They will be well aware that people around them are upset and that routines are disrupted. They will react in their individual ways. However, they can not be sheltered from the grieving. Regardless of people's religious beliefs, participating in the memorials and ceremonies after a death often helps the healing begin. Dr. Shawlow, after his wife died and when trying to help his son with autism, said, "What is done after a death is a very ancient ritual, deeply established by centuries of experience. I feel my son should be part of it." Sometimes it has helped the person with autism to see the person who has died, to experience that the person can no longer talk, eat, run, or hug.

Most people with autism are concrete in their thinking and gain understanding through experience. If they have experienced the death of an animal or someone they knew before the death of their parent, these experiences will be remembered. In our society, we too often shelter children and ourselves from experiences with death and expect people to go on with their lives soon after a death happens. Therefore, we are denied the opportunity to have an understanding of death and how it evolves as part of the cycle of life. *Lifetimes* is a simple, beautifully illustrated book that helps convey this idea. It's important to keep pictures, videos, and favorite belongings of the loved one available. These can be used over time to explain and remember. These items may also help a person with autism ask questions. Sometimes abstract ideas such as *living in heaven* or hearing that the person who has died has *gone to sleep* may be interpreted literally by a person with autism. The son or daughter may want to visit the parent in *heaven* or show fear of *going to sleep*. They may also try to go to the place where they last saw the parent or where they believe the parent is now. Being concrete and as specific as possible usually helps.

The person with autism is going to interpret events from his/her perspective and needs. Routines are disrupted. A person who knew them well and provided many supports for them may now be gone. Some type of behavior may be demonstrated by the person with autism to meet a need or communicate a feeling or frustration. One young man extended his routines when his Dad died so that his ritual for leaving the house required more than 15 minutes to complete. After the death of his dog Brownie, one person with autism kept repeating, "Die, funeral home, Uncle Bob, Granddad, Cousin Joe. Die Brownie, July 17." It took some detective work and understanding to realize that he was asking for information about why when Brownie died there was not a funeral home and relatives visiting. He had established his concept of what happens when someone dies from his experience with his Uncle Bob's death. Yet another person with autism began talking about dying and coming back as someone that everyone would like. The permanence of death is a complicated concept for many children and even most adults.

At this difficult time the person with autism is likely to need lots of reassurance, patience, and structure. There may be feelings of anger and hurt because a person they loved left them and this

anger may be expressed in a number of ways, sometimes directly toward the person who died. Old behaviors may resurface and there may be concern about regression. Be honest, be concrete and specific, and allow time. Provide stability, structure, and routine as much as possible. These are reassuring. Provide information in formats that the person with autism understands and realize that the whole process of understanding and acceptance will take a long time. Extend the idea of social stories to make a book about the person who has died. Compose social stories with pictures that suggest sequences and information about what is happening. A family does not need to go through this alone, but can accept offered help when they are comfortable with the offers and ask for help that they need. At the very time we feel people with autism may be the most vulnerable they sometimes surprise us with their insights and empathetic feelings. They may sense that others around them are distressed and may want to be close.

From all of us who are part of who we are because of our loved ones who have died, we offer sympathy and love to those who are suffering the pain of loss. People with autism need extra special understanding at this difficult time. This may require extra supports and time from those who know them well.

The internet offers many suggestions about books concerning children and young adults and death. The more visual books are often the most useful. Here are a few:

The Empty Place: A Child's Guide Through Grief by Temes, H. New Horizons Press (1992).
Everything You Need to Know When a Parent Dies by Bratman, F. Rosen Publishing Group (1998).

The Fall of Freddie the Leaf by Buscaglia, L. Slack, Inc. (1982).

The Grieving Child, A Parent's Guide by Fitzgerald, H. Simon & Schuster (1992).

The Happy Funeral by E. Bunting, Harper and Row, New York

Lifetimes by Mellonie, B. & Ingpen, R. Bantam Books (1987).

Living with Death by Bisignano, J. - ages 11 - adult.

Living with Death by Cera, M. J. - ages 4 - 10

published by Sheed and Ward Publishers, P.O. Box 40292, Kansas City, MO 64141.

A Quilt for Elizabeth by B. Tiffault, Centering Corporation, Omaha, NE (1992).

Saying Goodbye to Daddy by Judith Vigna, Albert Whitman & Col. Morton Grove, IL (1991)

Talking about Death by Earl Grollman. Beacon Press, Boston (1990)

The Two of Them by Alikei. Mulberry Books, New York (1979).

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STAR is an intervention program developed specifically for children and adolescents with autism spectrum disorders (ASDs) and their families. STAR is a program within the Weisskopf Center for the Evaluation of Children (WCEC), a division of the University of Louisville School of Medicine Department of Pediatrics.



