

Helping People With Intellectual Disabilities Cope With Loss

TIPS AND RESOURCES

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Grief is the price we pay for love
~C.M. Parkes

Individuals with intellectual disabilities experience grief when they lose a loved one just like everyone else.

Common misconceptions

- People with intellectual disabilities don't understand or can't comprehend death.
- People with intellectual disabilities don't show grief, therefore experience no grief.
- Talking about it would be too upsetting for him/her.

We now understand

- People with intellectual disabilities respond to bereavement and loss in essentially the same way as anyone else.
- The effects of bereavement may be prolonged with people with intellectual disabilities experiencing more anxiety, depression, irritability, and other signs of distress.

Expressions of grief

- Might be obvious such as sadness, crying, or depression.
- Might be the expression of emotions through behaviors such as irritability, sleep problems, anxiety, or expressions of fear.

Assisting in the grieving process

- Provide accurate and honest information
- Provide support to process it
- Enable maximum involvement in social and spiritual activities surrounding death
- Keep connections with key supportive relationships
- Maximize opportunities for expression of grief and condolences

Key strategies

- Provide reassurance
 - that there is no blame
 - on the ways things will be different
- Promote conversations about the loved one
 - to honor the lost life
 - to remember the love they shared
 - to think about what the person who has died might want for the individual
- Provide opportunities for the individual to make connections to the past, present and future:
 - Look at pictures and share memories
 - Make a book or a memory box about the person who died
 - Give them something that belonged to the person
 - Light a candle in honor of the person
 - Visit places they used to go together
 - Talk about how much the person who is gone would be happy about a present activity

Please see reverse for resources.



VANDERBILT KENNEDY CENTER
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

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RESOURCES

Who We Are and Who We Serve

The **Vanderbilt Kennedy Center** (VKC) works with and for people with disabilities and their family members, educators and service providers, researchers, students, and policy makers. Faculty and staff engage in interdisciplinary research, training, service, and information dissemination and work in collaboration with local, state and national networks and partners. (615) 322-8240, toll-free (866) 936-8852, vkc.vumc.org

Tennessee Disability Pathfinder

Tennessee Disability Pathfinder provides free information, referral sources, and help with navigating services via phone, email, and website. Assistance is available to individuals of all ages, all types of disabilities, and all languages spoken. Its website database has more than 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC and is partially funded by Tennessee Council on Developmental Disabilities and other state agencies. (615) 322-8529, toll-free (800) 640-4636, TNPathfinder.org

Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)

TRIAD is a VKC program dedicated to improving assessment and treatment services for children with autism spectrum disorders and their families while advancing knowledge and training. See TRIAD.vumc.org.

Other Resources

- **Alive Hospice** provides loving care to people with life-threatening illnesses, support to their families, and service to the community in a spirit of enriching lives. (800) 327-1085 www.alivehospice.org
- **The Boggs Center on Developmental Disabilities** provides community and student training and technical assistance, conducts research and model demonstrations, and disseminates information and educational materials. The Center coordinates a number of training and technical assistance activities related to aging, end of life, and grief/loss issues. rwjms.rutgers.edu/boggscenter/
- **Grief Speaks** conducts workshops, presentations, keynotes, and in-service trainings for schools, hospitals, businesses, agencies, communities, and organizations on the topics of coping with losses, transitions, and grief. Their Website has a section on “Grief and Children with Special Needs.” www.griefspeaks.com
- A series of picture books by Sheila Hollins, Lester Sireling, and Elizabeth Webb and published by Silent Books Ltd, include ideas for having discussions:
 - *When Mum Died*
 - *When Dad Died*
 - *When Someone Dies*
- Family Health Library, Junior League Family Resource Center, Monroe Carrell Jr. Children’s Hospital at Vanderbilt, www.childrenshospitalvanderbilt.org/information/family-resource-center

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