

Helping People With Intellectual Disabilities Cope With Loss

TIPS AND RESOURCES



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.



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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, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program. The following are some of the ways the Center's programs and staff can assist families, educators, and other service providers.

Tennessee Disability Pathfinder

Tennessee Disability Pathfinder is a free statewide phone, web, and print referral service in English and Spanish. It connects the Tennessee disability community with service providers and resources. Its website database has over 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC, TN Council on Developmental Disabilities, TN Department of Health, and the TN Department of Intellectual and Developmental Disabilities. Contact www.familypathfinder.org, (615) 322-8529, toll-free (800) 640-4636..

Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)

TRIAD is a Vanderbilt Kennedy Center program dedicated to improving assessment and treatment services for children with autism spectrum disorders and their families while advancing knowledge and training. See <http://TRIAD.vanderbilt.edu> or call (615) 936-0267.

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/ah_start.php

- **The Elizabeth M. 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.
<http://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/id96.html
- 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*
- Health Library, Jr. League family Resource Center, Monroe Carrell Jr. Children's Hospital at Vanderbilt,
www.vanderbiltchildrens.com/healthlibrary

The content of this tip sheet is based on a Vanderbilt Kennedy Disabilities, Religion, and Spirituality Program event that was co-sponsored by Alive Hospice. Content provided by Carol Rabideau.

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