



## Resources in Developmental Disabilities and Coping with Grief, Death and Dying

This does not pretend to be a complete listing of issues related to death and dying, but a partial listing of resources related to grief, death and dying for persons with intellectual and developmental disabilities and their caregivers, friends, and families..  
Compiled: by Bill Gaventa.

- ***Helping People with Developmental Disabilities Mourn: Practical Rituals for Caregivers.*** Marc Markell, Ph.D. Fort Collins, CO: Companion Press. Chapters exploring use of ritual with photographs, memory objects, storytelling, stones, light, plants, drawings, food, and other rituals drawn from daily life. Also see the website for a wide number of useful resources in grief and loss. [www.centerforloss.com](http://www.centerforloss.com).
- ***People Planning Ahead: Communicating Healthcare and End-of-Life Wishes.*** Leigh Ann Kingsbury. *People Planning Ahead* provides a comprehensive and structured way to ensure that loved ones receive care respecting their wishes and conforming to their personal, cultural, and religious beliefs during times of chronic and terminal illness, or severe disability. Accompanying CD-ROM contains electronic forms from Manual. [www.aaidd.org](http://www.aaidd.org).
- ***End of Life Care for Children and Adults with Intellectual and Developmental Disabilities.*** (2010) Ed. by Sandra Friedman, MD, MPH and David Helm, Ph.D. Washington: AAIDD. Sections on historical perspectives, medical conditions and management, controversies and ethical dilemmas, social, emotional and spiritual considerations, and supports and resources. 261pp.  
<https://aaidd.org/publications/bookstore-home/product-listing/end-of-life-care-for-children-and-adults-with-intellectual-and-developmental-disabilities#.VmcfBU2FO70>
- ***Helping Adults with Mental Retardation Grieve a Death Loss.*** Charlene Lucterhand, Nancy Murphy. Taylor and Francis Group, 7625 Empire Drive, Florence, KY 41042. 1-800-634-7064. \$22.95. An abbreviated form of this book is a booklet, *Mental Retardation and Grief Following a Death Loss: Information for Families and Other Caregivers.* 45 pp. Downloadable from [www.Thearc.org](http://www.Thearc.org) for members of their online community. (i.e., join, logout, wait for your notice, and then you can get into those publications).
- ***Guidebook on Helping Persons with Mental Retardation Mourn.*** Jeffrey Kauffman. Baywood Publishing Company, Amityville, New York. (800) 638-7819. Recognizing and conceptualizing grief in adults with developmental disabilities, guidelines for agencies, by a psychologist who has worked with many individuals and agencies. Now available in paperback for \$19.95 plus shipping. [www.baywood.com](http://www.baywood.com).
- ***Lessons in Grief and Death: Supporting People with Developmental Disabilities in the Healing Process.*** By Linda Van Dyke, this book includes counseling techniques and activities, including music, art, and drama, to work through the grieving process. Available from High Tide Press, 2505 E. Washington, Joliet, IL 60433. Order toll free at 1-800-469-9461 or visit [www.hightidepress.com](http://www.hightidepress.com).
- ***End-of-Life Care - A Guide for Supporting Older People with Intellectual Disabilities and Their Families - and Resource Supplement 2*** Volume Set - 2004; Anne L. Botsford, Ph.D. and Lawrence T. Force, Ph.D. A guide for supporting older people with intellectual disabilities and their families. Note – A

publication fee of \$19.95 plus tax where applicable (includes shipping), is charged for this publication. To order, contact the state office at 518-439-8311 or by email at [info@nysarc.org](mailto:info@nysarc.org)

- ***When Somebody Dies***. S.Hollins, S. Dowling, & N. Blackman. <http://booksbeyondwords.co.uk> Other titles in the *Books Beyond Words* series include ***When Mum Died, When Dad Died, Am I Going to Die?***, and ***Ann has Dementia***. Order from distributors: Turpin Distribution, tel 01767 604800, email: [custserv@turpin-distribution.com](mailto:custserv@turpin-distribution.com). The series includes many other titles related to daily living skills, self care, health care, life in the community and psychological issues.
- ***The Thinking Ahead, My Life At The End*** project was developed through a focus group made up of individuals with developmental disabilities. Advocates from three California Regional Centers: Alta California, Eastern Los Angeles, and Golden Gate, came together to talk about healthcare treatment and related end of life decisions. They shared about what was important to them and what they would need to make informed end of life decisions. The workbook and DVD contains words, symbols and pictures that facilitate discussion and decision-making regarding individual values, goals, and treatment preferences at the end of life. The Workbook and DVD are both available in three languages [English, Spanish and Chinese] free of charge through the California Coalition for Compassionate Care - <http://www.coalitionccc.org/thinking-ahead.php>. Digital PDF workbooks are available through California Department of Developmental Services - [www.dds.ca.gov/ConsumerCorner/Home.cfm](http://www.dds.ca.gov/ConsumerCorner/Home.cfm). See a video about the Thinking Ahead project and resource at <http://www.youtube.com/watch?v=pcs8BBQCbbs>.
- ***Ethical Issues, End of Life Considerations, and Developmental Disabilities***. Minnesota DD Council <http://www.mnddc.org>. Resources, including more than 50 short interviews with individuals, family members and others about end of life issues, and some videos including a news report about some of the things that have happened in the past (hopefully) in institutions both large and small.
- Complex and Moral Issues for End of Life Decisions for Adults with Significant Intellectual Disabilities <http://ucedd.georgetown.edu/complex/index.php>  
This website is for guardians of people with significant intellectual disabilities who have been given the responsibility to make decisions on behalf of people who as a result of their disability, have never expressed their intentions about their end-of-life care or preference for life-sustaining treatments. The resources and materials on this website will help guardians in making difficult and complex decisions about end-of-life care for adults with significant intellectual disabilities. The resources includes tools to assist in meetings with medical staff, assessing quality of life considerations and vignettes of various ethical issues. The tools are also helpful in supported decision making.
- ***Understanding Death and Illness and What They Teach About Life, An Interactive Guide for Individuals with Autism or Asperger's and Their Loved Ones***. Catherine Faherty. Arlington, Texas: Future Horizons. [www.FHautism.com](http://www.FHautism.com). Very detailed, explicit information and guides on how to use them in working with individuals on the spectrum. \$24.95. 300+pp.
- ***Dealing with Loss and Grief: A Team Approach***. This is CD-ROM based training directed to DSPs who support people who have both intellectual and mental health-based diagnoses. Here is an excerpt from the producer's description: "An introduction to the Grief Team model preparing professional staff to respond to sudden or anticipated deaths that occur while providing services to individuals, groups and families with Developmental Disabilities and/or mental health issues." From NADD, email [info@nadd.org](mailto:info@nadd.org). Website: <http://thenadd.org/> Go to Top 100 products and type in the name of the CD-Rom. \$18.95.

- ***End of Life Care: Bridging Disability and Aging with Person Centered Care.*** Ed. Bill Gaventa and David Coulter. (2005) Haworth Press. Binghamton, New York. Articles and resources related to both developmental disabilities and Alzheimer's. This was an issue of what is now the Journal of Religion and Disability. Volume 9: No. 2.  
<http://www.tandfonline.com/action/aboutThisJournal?journalCode=wrh21#.VwVWx2PnvNU>
- ***Supporting People with Intellectual Disabilities Experiencing Loss and Bereavement: Theory and Compassionate Practice.*** Ed. Susan Read. Jessica Kingsley Publications, Philadelphia. 2014. As the title notes, a collection of essays on both theory and practice. <http://www.jkp.com/supporting-people-with-intellectual-disabilities-experiencing-loss-and-bereavement.html>
- ***Caring for People with Learning Disabilities Who Are Dying.*** Noelle Blackman and Stuart Todd. Worth Publishing Centre and Welsh Centre for Learning Disabilities. Cardiff University, P.O. Box 28863, London, UK.
- ***Person-centered Planning for Late Life: A Curriculum for Adults with Mental Retardation.*** By H.L. Stern, E.A. Kennedy, C.M. Sed, & T. Heller. Institute for Life Span Development and Gerontology, University of Akron. Rehabilitation Research and Training Center on Aging with Mental Retardation, The University of Illinois. Price \$25. Web order: [www.uic.edu/orgs/rrtcamr/pubslst.html](http://www.uic.edu/orgs/rrtcamr/pubslst.html).
- ***Positive Approaches to Palliative Care.*** Amelia Jones and Irene Tuffrey-Wijne. Workbook from the UK published by BILD. (British Institute on Learning Disabilities.) [www.bild.org.uk](http://www.bild.org.uk).
- ***Ya Got People: Helping People with Developmental Disabilities Deal with Grief, Bereavement and Loss.*** Carolyn Bowling and Jeffery Wilder. 2003 Diverse City Press; ISBN1-896230-26-1
- ***NYSARC, Inc. Advocacy Monograph Number 4.*** 2008 - A collaborative project of NYSARC, Inc.; Hospice and Palliative Care of New York State; and Office of Mental Retardation and Developmental Disabilities The monograph represents a collaborative effort among professionals from the hospice and palliative care, developmental disabilities, legal and psychotherapy perspectives to offer a wide range of information. The monograph offers a cross systems training approach that enables staff in developmental disabilities agencies and staff in hospice and palliative care agencies to understand each other's systems and to build a team approach.. To obtain a copy of the monograph, contact the NYSARC, Inc. State Office at 518-439-8311 or by email at [info@nysarc.org](mailto:info@nysarc.org).

#### **Other Resources:**

***Grief, Loss, and End of Life.*** A department of the online resource bank, The Quality Mall. <http://www.qualitymall.org/directory/dept1.asp?deptid=87&code=62711&id=5110> . This department features materials that help people with disabilities and others deal with serious health and/or end of life issues. This topic is often associated with aging, but there is also information especially for young people, parents and caregivers.

***African American Faith Based Bereavement Initiative:*** A curriculum o respond to the needs of families within their faith community, the National Center for Cultural Competence - Sudden Unexpected Infant and Child Death and Pregnancy Loss Project (SUID/CD/PL) and National SUID/CD/PL Program Support Center at First Candle have partnered to create the African American Faith-Based Bereavement Initiative (AAFBBI.) The AAFBBI was created specifically for the African American Christian faith community to

improve supports for families experiencing these losses.

<http://nccc.georgetown.edu/AAFBI/index.html>

**Last Passages**, a national project focusing on end of life care, grief and loss with adults with developmental disabilities. [www.albany.edu/aging/lastpassages](http://www.albany.edu/aging/lastpassages). Resource guide, policy recommendations.

**What Can I Do? Ideas to Help Those Who Have Experienced Loss**, Barbara Glanz. Minneapolis, Augsburg Books, 2007. Written for the general public, but very practical, hands-on suggestions.

**Voice Quilt**. <http://www.voicequilt.com/> A website that helps create personalized keepsakes of friends' and family voices. Particularly a resource for saying goodbye to someone who is moving, retiring, etc.

**Beyond Casseroles. 505 Ways to Encourage a Chronically Ill Friend**. Lisa Copens. [www.restministries.org](http://www.restministries.org)  
<http://illnessbooks.com/Books-By-Lisa/Beyond-Casseroles-505-Ways-Encourage-a-Chronically-Ill-Friend-p178.html>

**The Geese and the Peanut Butter Chocolate Ice Cream: The Grieving Gifts to the Lexington Street Community--A Resource to Help Individuals with Developmental Disabilities and People Who Support Them Grieve the Death of Loved Ones**. This resource helps people deal with death, loss and the process of grief by showing how people support and nurture each other. The story describes the responses of staff, family, neighbors and individuals in a group home after a sudden death of an individual with a developmental disability. Other sections include: Reflection and/or Discussion Questions, Practical Strategies for Dealing with Loss, Death, and Grief, Activity Book, Game, and Bibliography. The resource can be used as one complete package or as individual sections. 2006. 90 pages. PDF only. Download free from The Boggs Center website: [http://rwjms.umdj.edu/boggscenter/products/prod\\_info.htm#grief](http://rwjms.umdj.edu/boggscenter/products/prod_info.htm#grief)

### **Additional Resource Listings**

#### **The Quality Mall (This is an excellent listing of additional resources)**

Go to [www.qualitymall.org](http://www.qualitymall.org) and to the "Grief, Loss, and End of Life Department".

<http://www.qualitymall.org/directory/dept1.asp?deptid=87> Example: "Supporting Adults with Intellectual Disability Through Bereavement and the Grief Process"

<http://www.qualitymall.org/products/prod1.asp?prodid=29110>

### **Online Webinars and Courses**

#### **The ARC.**

"Being With" People with I/DD Experiencing Grief and Loss, Archived webinar by The ARC Future Planning Project. [Link to Archived Webinars](#)

#### **Association for Clinical Pastoral Education**

**Dimensions of Grief and Loss in the Lives of People with Intellectual and Developmental Disabilities and Pastoral Strategies for Addressing Them**

Presenter(s): Bill Gaventa and Meggie Kobb

Presented on: May 10, 2016

## AAIDD Education Archives

- <https://aidd.org/education/education-archive/2015/07/14/default-calendar/grief-and-loss-in-individuals-with-dual-diagnosis>
- <https://aidd.org/education/education-archive/2015/03/19/default-calendar/end-of-life-care-for-people-with-intellectual-and-developmental-disabilities#.VwVlaGPvNU>

## Hospice Foundation of America

- 2 hr. Self-Study Course - Support of People with Intellectual and Developmental Disabilities. <https://register.hospicefoundation.org/programs/self-study-courses-for-individuals>

## Other On-Line Resources and Websites

An email discussion about resources to support a young man with autism dealing with the suicide of his father led to other emails with resources that Karen Jackson of the Faith Inclusion Network (<http://www.faithinclusionnetwork.org>) collected for all of our use:

<http://www.qualitymall.org/products/prod1.asp?prodid=29110>  
<http://www.pathfindersforautism.org/articles/view/parent-tips-death-and-grieving>  
<https://www.autismspeaks.org/family-services/resource-library/bereavement-and-grief-resources>  
<http://www.autismsocietyph.org/how-to-talk-to-children-with-autism-about-death/>  
<http://www.autism.org.uk/bereavement>  
<http://www.friendshipcircle.org/blog/2013/08/20/how-to-talk-to-your-child-with-special-needs-about-death/>  
<http://autismdigest.com/an-aspies-view-of-death/>  
<http://www.griefspeaks.com/id96.html>  
[http://autism.lovetoknow.com/Being\\_Autistic\\_and\\_Dealing\\_with\\_Death](http://autism.lovetoknow.com/Being_Autistic_and_Dealing_with_Death)  
<https://expertbeacon.com/helping-kids-autism-spectrum-disorder-navigate-bereavement#.VpmOuPkrIgs>  
[http://parenting.blogs.nytimes.com/2010/11/04/making-sense-of-death-and-autism/?\\_r=0](http://parenting.blogs.nytimes.com/2010/11/04/making-sense-of-death-and-autism/?_r=0)  
<http://www.amazon.com/Understanding-Death-Illness-Teach-about/dp/1932565566>  
<http://blog.stageslearning.com/blog/understanding-death?topic=autism-emotions>  
<http://www.pathfindersforautism.org/docs/social-story-about-death.pdf>  
<http://benziesangmassocialstoriesforautism.blogspot.com/2013/05/when-someone-dies.html>  
<http://www.archildrens.org/Services/Center-for-Good-Mourning/Good-Mourning-Resources.aspx>