



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 mental retardation or other disabilities and their families. Compiled: by Bill Gaventa, M.Div., Associate Professor, email: Bill.gaventa@umdnj.edu. (Revised, 3/11)

- 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.
- 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.aaid.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. <http://bookstore.aaid.org>.
- 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 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.
- 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

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- When Somebody Dies. S.Hollins, S. Dowling, & N. Blackman. *Books Beyond Words*, Gaskell/St. George's Hospital Medical School-Royal College of Psychiatrists. 2003. Price \$20. Other titles in the *Books Beyond Words* series include *When Mum Died*, *When Dad Died*, and *Am I Going to Die?* RCPsych Publications now sells over 140 titles. Many new book web pages feature contents lists and sample chapters: <http://www.rcpsych.ac.uk/publications/booksbeyondwords.aspx>. In addition, you can now also buy RCPsych Publications and *Books Beyond Words* titles via <http://www.amazon.com/>. North American distributor for Royal College of Psychiatrists. Contact details: Publishers Storage and Shipping Company, 46 Development Road, Fitchburg, MA 01420, USA. Email: orders@pssc.com Tel: +1-978-829-2560. Fax: +1-978-348-1233. PSSC can take credit card orders from both individuals and orders from book shops.
- 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. See a video about the Thinking Ahead project and resource at <http://www.youtube.com/watch?v=pcs8BBQCbbs>.
- 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. Very detailed, explicit information and guides on how to use them in working with individuals on the spectrum. \$24.95. 300+pp.
- 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.
- 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.
- 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.
- 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/rtrcamr/pubslst.html.

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- Grief and Loss Workbook. For adults with developmental disabilities. Christian in focus. Bethesda Lutheran Homes and Services. <http://www.blhs.org/resources/SpiritualResources/pdfs/> .
- 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.
- 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.

Other Resources:

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

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.umdnj.edu/boggscenter/products/prod_info.htm#grief

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

Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and Their Families. A Bibliography and Address Listing of Resources. Section of materials on grief, death, and dying. at http://rwjms.umdnj.edu/boggscenter/products/%20documents/dimensions_of_faith.pdf.

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..

The **AAIDD**, has a national action group working on End of Life Issues. For more information, visit the www.aidd.org. In New Jersey, The Boggs Center coordinates a listserv, **NJAELDD**, New Jersey Aging and End of Life in Developmental Disabilities.. It is free. To join, email Beth Ong at ongel@umdnj.edu.

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