

VI. A) SPECIAL ISSUES IN PASTORAL CARE: 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 disabilities or other disabilities and their families. There are a great number of articles related to ethical and treatment issues for persons with mental retardation and disabilities, but these focus more on articles and resources that may be of particular help in pastoral care. A national project entitled Last Passages also focused on grief, loss, and end of life care with people with intellectual disabilities. For more information, see Last Passages. A three year project coordinated by the Volunteers of America regarding end of life care. Website: www.albany.edu/aging/lastpassages

- 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.
- Helping Adults with Mental Retardation Grieve a Death Loss. Charlene Lucterhand, Nancy Murphy. \$16.95, Accelerated Marketing, 47 Runway Road, Levittown, PA 19057, Phone: (800) 821-8312.
 - 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. \$6.49. Available from The Arc. www.TheArcPub.com.
- Noelle Blackman and Stuart Todd. Caring for People with Learning Disabilities who are Dying. Worth Publishing, London. An introductory guide for front line staff and service managers for providing good end-of life care. Available for £6 from WCLD, Cardiff University, Meridian Court, North Road, Cardiff, CF14 3BG Tel: 029 20691795 Fax: 029 20610812.
- Palliative Care for People with Learning Disabilities (Ed. Sue Read) Cost £29.99 Quay Books, Salisbury, Wilts. UK.
- Person-Centered Planning for later Life: Death and Dying. A curriculum for Adults with Developmental Disabilities. Five in-class lessons and one field trip. Instructor Guide and Student Notebook. Lessons are Understanding Death, Grief, Mourning/Comfort/Support, Death Related Rituals-Funerals. \$25. \$12.50 for additional Trainer's Guides. Check or money order to Institute on Disability and Human Development, send to Clearinghouse on Aging and Developmental Disabilities, Department of Disability and Human Development, The University of Illinois at Chicago, 1640 West Roosevelt Road, Chicago, IL 60608-6904.

DIMENSIONS OF FAITH: SPECIAL ISSUES IN PASTORAL CARE: GRIEF, DEATH AND DYING

- End-of-life Care: A Guide for Supporting Older People with Intellectual Disabilities and their Families. By A.L. Botsford and L.T. Force. Purchase price: \$21. From NYSArc, Inc, 393 Delaware Ave., Delmar, NY 12054. Phone: 518-439-1893. Email: nysarc@crisny.org.
- Books Beyond Words. My Mom Died. My Father Died. When Someone Dies. A collection of books with picture drawings designed to assist people with intellectual difficulties in coping. No words. Designed to be looked at with a support person or counselor, and talked about. Other topics include depression, a move to a new home, going to the hospital, etc. Book Sales, Royal College of Psychiatrists, or from Mariah Management, 1153 Bergen Park Way, #M438, Evergreen, CO 80439. \$18 each or \$225 for set of 14.
- "Helping Each Other When People Die." (Student and Leader Versions) is an adult religious education module developed by Friendship Ministries, and one of their most heavily ordered resources. Friendship Ministries.
- "Journey into Understanding Mentally Retarded People's Experiences Around Death." Muriel Carder. The Journal of Pastoral Care. March, 1987. Vol. XLI, No. 1.
- 25 Things to Do When Grandpa Passes Away, Mom and Dad Get Divorced, or the Dog Dies: Activities to Help Children Suffering Loss or Change. Parenting Press, Inc., Seattle, www.parentingpress.com, (800) 992-6657, \$13.95.
- Grief and Faith: Spiritual Paths Through Loss. 20 pp. Booklet from American Hospice Foundation. \$3 each. Discounts on multiple copies.
- "Bill: The Life of A Man." Wolf Wolfensberger. Article in Mental Retardation, Vol. 27, No. 6, December, 1989.
- The Centering Corporation has an excellent collection of resources related to grief for families, death and dying, children's awareness, teens, parents, spouse, coping with grief, and caregiving. Contact them for a catalogue with the resources they distribute.
- Children Facing Grief. Letters from Bereaved Brothers and Sisters. Jan Romond. Written for children. Abbey Press.
- "Communicating About Loss and Mourning: Death Education for Individuals with Mental Retardation." Mental Retardation, 31.3. (June, 1993), pp. 144-47.
- Death and Dying: A Guide for Staff Serving Adults with Mental Retardation. Mary Howell, Thomas Barbara, and Richard Pitch. Exceptional Parent Press. 1989. \$7.95.

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- What Happens After We're Gone? by Duane Ruth-Heffelbower. Mennonite Mutual Aid, 1996. \$4.00. Helps families with estate planning, wills, trusts and guardianships for their dependants with a disability or mental illness. Encourages church involvement. Available from www.adnetonline.org.
- How Will I Get Through the Holidays: 12 Ideas for Those Whose Loved One Has Died. James E. Miller. Willowgreen, (260) 490-2222, www.willowgreen.com. 64 pp. \$6.95.
- Helping the Bereaved Celebrate the Holidays. Directions for designing community events to support mourners during a trying time of the year. Willowgreen, (260) 490-2222, www.willowgreen.com. 96 pp. \$7.95.
- Dealing with the end of life, by A.L. Botsford in *Community Supports for Aging Adults with Lifelong Disabilities* (pp. 415-429). Order from Brooks Publishing Co. at <http://www.brookespublishing.com/store/index.htm>. Price: \$58.
- The Last Dance: Encountering Death and Dying. By L.A. DeSelder & A.L. Strickland from Mayfield Publishing.
- Bereavement in the Lives of People with Intellectual Disabilities. Learning about Intellectual Disabilities and Health. By S. F. Dowling. Web resource that can be view on website: <http://www.intellectualdisability.info/lifestages/bereavement.htm>.
- Demography of family household, by G. Fujiura. Can be found in *American Journal on Mental Retardation*, 103 (3), 1998.
- Later life planning: Promoting knowledge of options and choice-making. By T. Heller, A.B. Miller, K. Hsieh, & H. Sterns. In *Mental Retardation*, 38 (5), 395-406, 2000.
- Managing grief better: People with developmental disabilities. By S. Hollins. In *The Habilitative Mental Health Newsletter*, 14, May/June 1995.
- Bereavement and Grief in Adults with Learning Disabilities. S. Hollins & A. Esterhuyzen. In *British Journal of Psychiatry*, 170, 497-501, 1997.
- On Death and Dying. E. Kubler-Ross. NY: Touchstone, 1997.
- An examination of the knowledge and understanding of health and social care staff about the grieving process in individuals with learning disability. By G.C. Murray, K. McKenzie, & A. Quigley. In *Journal of Learning Disabilities*, 4 (1), 77-90, 2000.
- Treatment of Complicated Mourning. By T.A. Rando. Champaign, IL: Research Press, 1993.

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- Helping Children Cope with Death. By C.L. Roberts. In *Educational Leadership*, 2, 409-411, 1981.
- Quality of Life differences between adults with and without disabilities. D.J. Sands & E.B. Kosleski. In *Education and Training in Mental Retardation and Developmental Disabilities*, 29, 90-101, 1994.
- Psychological Adjustments in Midlife. By G. Seltzer. Found in book *Older Adults with Developmental Disabilities*. Baltimore, MD: Brooks Publishing Co.
- Later-life planning and retirement. By H.L. Stern, E.A. Kennedy, C.M. Sed, & T. Heller. In *Community Supports for Aging Adults with Lifelong Disabilities*, pp. 179-191. Baltimore, MD: Brooks Publishing Co.
- Communication about Loss and Mourning: Death Education for Individuals with Mental Retardation. By J. Yanok & J.A. Beifus. In *Mental Retardation*, 31, 144-147, 1993.
- Nonfinite Loss and Grief. A Psychoeducational Approach. EJ Bruce and CL Schultz. Grieving of eight individuals experiencing nonfinite loss, with suggested therapeutic techniques. Brookes Publishing.
- Living with Grief. Who We Are, How We Grieve. Ken Doka, Ed. Book based on annual teleconference of the Hospice Foundation of America. Includes a chapter on grief and persons with developmental disabilities. \$16.95. Hospice Foundation of America. They also have a number of other books and videotapes on grief, death, and dying.
- Bihm, E. and Elliott L. "Conceptions of Death in Mentally Retarded Persons." Journal of Psychology 111 (1982), pp. 205-210.
- Deutsch, H. "Grief Counseling with Mentally Retarded Clients." Psychiatric Aspects of Mental Retardation Reviews 4 (1985), pp. 17-20.
- "Grief in Adults with Mental Retardation: Preliminary Findings" Dennis Harper and John Wadsworth. Published in Research in Developmental Disabilities. For copy, contact Division of Developmental Disabilities, Department of Pediatrics, University Hospital School, 100 Hospital School, Iowa City, Iowa 52242-1011.
- Serving the Underserved: Caring for People Who are Both Old and Mentally Retarded. Editors: Mary Howell, Deirdre Gavin, Gerard Cabrera, Henry Beyer. Boston: Exceptional Parent Press, 1989. Includes chapters on "Grief Counseling," "A Developmental Approach to Cognitive Understanding of Death and Dying," "Funeral and Memorial Services," "Training Staff to Care for Dying Clients," and "A Support Group on the Issues of Death and Dying with Mentally Retarded Adults."

DIMENSIONS OF FAITH: SPECIAL ISSUES IN PASTORAL CARE: GRIEF, DEATH AND DYING

- NAPMR Quarterly Publication, Fall, 1993 had a number of articles related to death, dying, grief, and helping people with mental retardation cope with loss. Contact National Apostolate for Inclusion Ministry.
- A Guideline for Protecting the Health and Lives of Patients in Hospitals, Especially if the Person is a Member of a Societally Devalued Class. Wolf Wolfensberger. Syracuse University Training Institute, 805 South Crouse Ave., Syracuse, N.Y. 13244-2280. Attn: Book Manager. \$6.50. Or call 315/443-4264.
- Assisting Bereaved Individuals. Video presentation featuring Nancy Kirchner, Irwin Levy, John Wadsworth, Fred Stiemke at Panel Presentation and Discussion at AAMR National Conference, New Orleans. 1992. Two videotapes. Rental \$10 from AAMR Religion Division.
- Surviving Death: A Practical Guide to Caring for the Dying and Bereaved. Charles Meyer. Twenty-Third Publications, 1995.
- "Health Care Decision Making Guidelines for Adults with Developmental Disabilities", in Ethical Issues in the Health Care of Persons with Developmental Disabilities. From Midwest Bioethics Center, 1021-1025 Jefferson St., Kansas City, MO 64105-1329.
- Fierce Goodbye: Living in the Shadow of Suicide. A video also available on DVD., with four session study guide. Five families and their stories. Narrated by Judy Collins. 44 min. From website: www.fiercegoodbye.com.
- Assisted Suicide and the Quality of Life of Persons with Disabilities. John Pipe. Issued by the National Council of Churches Committee on Disabilities, January 2000. Education Cluster, Room 848, 475 Riverside Drive, New York, NY 10115-0050

RESOURCES FROM HOSPICE FOUNDATION OF AMERICA

The Hospice Foundation of America has a variety of resources and materials, including a monthly email newsletter. A number of books focus on Living with Grief, an annual resource related to their annual national teleconference. Titles include:

- Living with Grief: After Sudden Loss
- Living with Grief: Illness Prolonged
- Living with Grief: Who We Are, How We Grieve
- Living with Grief: At Work, At School, At Worship
- Living with Grief: Children, Adolescents, and Loss
- Caregiving and Loss: Family Needs, Professional Responses

RESOURCES FROM BASIS

- The Pastor-A Vital Part of the Healing Process. Suggestions for pastors in helping individuals through the healing process. BASIS, 309 Colonial Drive, P.O. Box 249, Akron, PA 17501-0249. (717) 859-6404 or (888) BCM-INTL. FAX: (717) 859-6914.
- “Help for People in Pain,” A three-hour seminar designed to describe the process of grief and to suggest ways individuals can learn to cope with loss situations and to encourage the local church to reach out to those in pain. BASIS, 309 Colonial Drive, P.O. Box 249, Akron, PA 17501-0249. (717) 859-6404 or (888) BCM-INTL. FAX: (717) 859-6914.
- “Living with a Sovereign God in a Sour World,” A three-hour follow-up seminar designed to help individuals move beyond the painful feelings to where God fits into the situation. BASIS, 309 Colonial Drive, P.O. Box 249, Akron, PA 17501-0249. (717) 859-6404 or (888) BCM-INTL. FAX: (717) 859-6914.
- Keeper of the Stars, Healer of Hurting Hearts: Meditations for Bereaved Parents and Their Families. A book of devotions written by bereaved parents for bereaved parents. BASIS, 309 Colonial Drive, P.O. Box 249, Akron, PA 17501-0249. (717) 859-6404 or (888) BCM-INTL. FAX: (717) 859-6914.
- Stars of Promise: Meditations for Bereaved Parents. A book of devotions written by bereaved parents for bereaved parents. BASIS, 309 Colonial Drive, P.O. Box 249, Akron, PA 17501-0249. (717) 859-6404 or (888) BCM-INTL. FAX: (717) 859-6914.
- Promesas de Esperanza para Corazones Quebrantados. A book of devotions written by bereaved parents for bereaved parents. Spanish version. BASIS, 309 Colonial Drive, P.O. Box 249, Akron, PA 17501-0249. (717) 859-6404 or (888) BCM-INTL. FAX: (717) 859-6914.

AUDIO-TAPE SERIES ON GRIEF:

- New Jersey Developmental Disabilities Series. Speaker Charlene Lucterhand, author of Helping Adults with Mental Retardation Grieve a Death Loss. 3 hour tape available for rental from Rachel Scalise at 732-235-9300.
- Clergy to Clergy. Six audio-tapes featuring Ken Doka and Paul Irion, covering many issues and aspects of grief, death, funerals, etc. Title is deceptive, because it is very useful for any caregiver seeking to understand more about coping with grief. \$20. Hospice Foundation of America.