



## Person-Centered Decision Making in Healthcare and Care at End-of-Life Webinar List of Resources

### Resource Recommended by Diane Coleman:

- *A New Paradigm Is Needed: Top Experts Question the Value of Advance Care Planning*: <https://khn.org/news/article/advance-care-planning-palliative-care-experts-paradigm-shift/>

### Resources Recommended by Tawara Goode:

- Goode, T. D. & Maloof, P. End-of Life through a Cultural Lens. (2010). In Friedman, S. and Helm, D. (Eds.) *End-of Life Care for Children and Adults with Intellectual and Developmental Disabilities*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Belisomo, R. (2018). Reversing racial inequities at the end of life: A call for health systems to create culturally competent advance care planning programs within African American communities. *Journal of Racial and Ethnic Health Disparities*, 5(1), 213–220. <https://doi.org/10.1007/s40615-017-0360-2>
- Boucher, N. A., & Johnson, K. S. (2021). Cultivating cultural competence: How are hospice staff being educated to engage racially and ethnically diverse patients? *American Journal of Hospice and Palliative Medicine®*, 38(2), 169–174. <https://doi.org/10.1177/1049909120946729>
- Boucher, N. A. (2016). Direct engagement with communities and interprofessional learning to factor culture into end-of-life health care delivery. *American Journal of Public Health*, 106(6), 996–1001. <https://doi.org/10.2105/AJPH.2016.303073>
- Ornstein KA, Roth DL, Huang J, et al. Evaluation of Racial Disparities in Hospice Use and End-of-Life Treatment Intensity in the REGARDS Cohort. *JAMA Netw Open*. 2020;3(8):e2014639. doi:10.1001/jamanetworkopen.2020.14639
- Orlovic, M., Smith, K., & Mossialos, E. (2018). Racial and ethnic differences in end-of-life care in the United States: Evidence from the Health and Retirement Study (HRS). *SSM - population health*, 7, 100331. <https://doi.org/10.1016/j.ssmph.2018.100331>
- *Denied the right to comfort: Racial inequities in palliative care pro*: [https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370\(21\)00113-9/fulltext](https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00113-9/fulltext)
- Complex Moral Issues: End of Life Decisions for Adults with Significant Intellectual Disabilities. (n.d.). Georgetown University Center for Child and Human Development. Retrieved from <https://ucedd.georgetown.edu/complex/>
- Silva, M. D., Genoff, M., Zaballa, A., Jewell, S., Stabler, S., Gany, F. M., & Diamond, L. C. (2016). Interpreting at the end of life: A systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited english proficiency. *Journal of Pain and Symptom Management*, 51(3), 569–580. <https://doi.org/10.1016/j.jpainsymman.2015.10.011>



- Goode, T., Jones, W., & Christopher, J. Brown, I., Responding to Cultural and Linguistic Differences among People with Intellectual Disability (2017). In Percy, M., Wehmeyer, M. L., Shogren, K. A., & Fung, A. (Eds.) A comprehensive guide to intellectual and developmental disabilities (2nd ed.). Baltimore, MD: Brookes Publishing, pp. 389-400.
- Yee, S., Breslin, M.L., Goode, T.D., Havercamp, S.M., Horner-Johnson, W., Iezzoni, L., & Krahn, G. (2018). *Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity*. Washington, DC: National Academies of Sciences, Engineering, and Medicine.

#### Resources Recommended 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).
- ***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://aaid.org/publications/bookstore-home/product-listing/end-of-life-care-forchildren-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).
- ***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.
- ***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=wrhd21#.VwVWx2PnvNU>
- ***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
- ***Disability and Spirituality: Recovering Wholeness.*** Bill Gaventa. [Baylor University Press](http://www.baylorpress.com). One of the chapters is on aging and end of life issues.
- ***Supporting Someone with a Learning Disability.*** A guide for funeral home directors from the UK.

### Two Short Books full of Concrete Ideas, focused on Everybody

- ***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.
- ***Beyond Casseroles. 505 Ways to Encourage a Chronically Ill Friend.*** Lisa Copens. [www.restministries.org](http://www.restministries.org)

### Planning and Making Decisions about End of Life

- ***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/pubslist.html](http://www.uic.edu/orgs/rrtcamr/pubslist.html).



- ***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>. A number of states have adapted this to fit their own state. So when you google the title, you'll see.
- ***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 (*Out of print but still worth looking for*)
- ***Living Well: Using Person Centered Thinking Tools with People Who Have a Life Limiting Illness***. Helen Sanderson and Gill Bailey, Helen Sanderson Associates, 2010. Living Well is a person-centered approach to supporting people to live well with a long-term condition. It also provides a structure to help people think about and plan for the end of life. This site includes information about the Living Well workbook and Madge's story of planning for care at the end of life. <https://helensandersonassociates.com/person-centered-approaches/living-well/> and <https://helensandersonassociates.com/wp-content/uploads/2022/02/livingwell-hull.pdf>
- **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.
- ***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).
- **Advance Care Planning for Individuals With Intellectual and Developmental Disabilities: A State-by-State Content Analysis of Person-Centered Service Plans** An



article in the August 2021 issue of *Intellectual and Developmental Disabilities* by authors affiliated with Binghamton University, Eastern Michigan University, Brock University, and University of Wisconsin-Madison, discusses a content analysis used to examine data from public documents across the United States to identify the frequency of advance care planning in person-centered planning and the ways it manifests. (abstract free of cost, full text access available with a fee)

### Social Stories with Simplified English and Adult themed Illustrations (drawings)

- ***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.
- Similar. From Scotland. <https://www.mariecurie.org.uk/help/support/publications/all/easyread-feelings-when-someone-dies>. A down-loadable, simple language with adult illustrations booklet. Also excellent.

### Websites

- ***Talking about End of Life (with people with intellectual and developmental disabilities)*** A website from a project in Australia devoted to resources, training modules, and videos for people working directly with people with intellectual and developmental disabilities. Developed by some excellent researchers. Don't overlook this one: <https://www.caresearch.com.au/tel/tabid/4881/Default.aspx>
- ***Ageing and Disability***. A website developed by L'Arche of Canada with resources, videos, and more that address aging, end of life, and grieving issues. <http://www.ageing-and-disability.org/>
- ***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.
- ***Living Well but Dying Matters***: UK website: <https://www.dyingmatters.org/page/people-learningdisabilities?fbclid=IwAR1BnndQFwZRn4z8LPMijOwSojhsNxWkeQfFi2kzhc1ExR91UbMJvg58M4>. Video and other resources.
- ***Irene Tuffrey Wijne*** The website for one of the leading researchers and writers in this arena in the UK. It opens with a recent webinar, but also see the videos on Talking with Adults with IDD about Death. She is the author of several of the *Beyond Words* booklets. <http://www.tuffrey-wijne.com>
- ***Coming in 2022***. A website for autistic adults, their families and friends, caregivers, and professionals on grief, loss, and end of life issues. The Hospice Foundation of America.

**Archived Webinars (A sampling)**

- The ARC Future Planning Project: <https://futureplanning.thearc.org/pages/learn/where-to-start/webinars/archived-webinars>
  - *“Being With” People with I/DD Experiencing Grief and Loss*, Archived webinar by The ARC Future Planning Project. [Link to Archived Webinars](#)
  - *Grief and Loss in the Lives of People with Intellectual and Developmental Disabilities*
- 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
- **Hospice Foundation of America**
  - 2 hr. Self-Study Course - *Support of People with Intellectual and Developmental Disabilities*.
- **Palliative Care for People with Learning Disabilities, UK**
  - [Researching Complicated Grief in People with Learning Disabilities](#) University of Dublin

**Articles Online**

(This is just a sampling. If one searches for “Grief, Bereavement, Intellectual Disability, Learning Disability, Death, or any combination of those terms, the array of resources compared to when this listing started about ten years ago is simply amazing.)

<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.friendshipcircle.org/blog/2013/08/20/how-to-talk-to-your-child-with-special-needsabout-death/>

[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)

[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://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>

**Training**

*Using Person Centered Practices to Support Advance Care Planning and Care at End of Life.*

Be notified of upcoming facilitator training series with Leigh Ann Kingsbury and Mary Beth

Lepkowsky <https://lp.constantcontactpages.com/cu/taKH68x>