

# RESOURCES

## INTELLECTUAL/DEVELOPMENTAL DISABILITIES AND GRIEF, DEATH, & DYING

A compilation of articles, books and blogs available to supplement your knowledge, skills and abilities to support people with intellectual and developmental disabilities as they grieve anticipated and/or experienced losses through others or their own processes of death and dying.

- **Managing Grief Better: People With Intellectual Disabilities**  
<http://www.intellectualdisability.info/mental-health/articles/managing-grief-better-people-with-intellectual-disabilities>
- **Bereavement In The Lives Of People With Intellectual Disabilities**  
<http://www.intellectualdisability.info/life-stages/articles/bereavement-in-the-lives-of-people-with-intellectual-disabilities>
- **How to Talk to Someone with an Intellectual Disability about Death, Even if You Aren't Sure You Should**  
<http://reifpsychservices.com/talk-to-someone-with-intellectual-disability-about-death/>
- **Supporting Somebody with an Intellectual Disability Through Grief**  
<https://www.funeralguide.com/blog/intellectual-disability-grief>
- **Individuals with Intellectual Disabilities: Struggling with Loss and Grief**  
<http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.604.9954&rep=rep1&type=pdf>
- **Helping People with Developmental Disabilities Mourn: Practical Rituals for Caregivers**  
focuses on creating mourning rituals for people with developmental disabilities because frequently they are excluded from bereavement ceremonies when a loved one or friend dies. This guide offers more than 20 examples of specific rituals and techniques for (cont'd) caregivers to use while helping explain death and dying and providing opportunity to comprehend feelings of loss. <https://www.amazon.com/Helping-People-Developmental-Disabilities-Mourn/dp/1879651467>
- **Making Sense of Death and Autism in a NY Times Parenting Blog**  
<https://parenting.blogs.nytimes.com/2010/11/04/making-sense-of-death-and-autism/>

- **Ya Got People: Helping People with Developmental Disabilities Deal with Grief, Bereavement and Loss** aims at providing the reader with insight into the issue of grief for those in care as well as teaching approaches to compassionately support an individual with a disability suffering a loss. It approaches the topics with humor as well as examples. <https://www.cavershambooksellers.com/search/1896230261>
- **What Can I Do? Ideas to Help Those Who Have Experienced Loss** is a collection of simple, concrete ideas gathered directly from those who have experienced suffering and loss, ideas of things that helped them feel cared for and comforted. <https://barbaraglanz.com/products/books/what-can-i-do-ideas-to-help-those-who-have-experienced-loss/>
- **Lessons in Grief and Death: Supporting People with Developmental Disabilities in the Healing Process** features a three-fold approach: a description of the grief counseling process; dozens of activities—including art, music, and drama— that can be used to help a person through the grief process; nine uplifting stories of real individuals coping with a variety of deaths losses. <https://cherryhillhightide.com/product/lessons-in-grief-death/>
- **Hospice Foundation Self-Study DVD or ONLINE Course Supporting Individuals with Intellectual and Developmental Disabilities Through Serious Illness, Grief and Loss** addresses the ethical, medical management and psychosocial issues for individuals with intellectual and developmental disabilities facing death, grief and loss. This two-hour educational event focuses on the critical challenges of providing and accessing optimal end-of-life care and bereavement support for this population. [http://hospicefoundation.org/getmedia/4301d13c-1749-4cf1-92ad-f10e49777e73/ProgramInfo\\_SSID](http://hospicefoundation.org/getmedia/4301d13c-1749-4cf1-92ad-f10e49777e73/ProgramInfo_SSID)
- **Pathfinders for Autism Parent Tips Article: Death and Grieving** includes suggestions for explaining death, funerals, and loss to persons with autism as well as links to additional resources on loss, death and grieving for those with ASD. <https://pathfindersforautism.org/articles/home/parent-tips-death-and-grieving/>
- **The Geese and the Peanut Butter Chocolate Ice Cream: The Grieving Gifts to the Lexington Street Community** is a resource to help individuals with developmental disabilities and people who support them grieve the death of loved ones.: <http://rcgnc.com/WellnesLibrary/DD-MR%20Specific%20Tools/The%20Geese%20and%20Chocolete%20PB%20Ice%20Cream.pdf>
- **Helping Adults with Mental Retardation Grieve a Death Loss** is a guide designed to help professionals give adults with intellectual disabilities the opportunity to grieve the loss of their loved ones. <https://www.amazon.com/Helping-Adults-Mental-Retardation-Grieve/dp/1560327685>
- **New Jersey Virtual Family Assistance Center Integrated Condolence Care Program** through the American Red Cross provides residents who have lost a loved one to COVID-19 with information and resources. <https://www.redcross.org/virtual-family-assistance-center/nj-family-assistance-center.html>

- **Guidebook on Helping Persons with Mental Retardation Mourn** contributes to an awareness of the significance of loss in the life experience of persons with intellectual disabilities. Experiencing loss may be a very powerful vulnerability in their mental or psychological life, and dealing with this loss is a basic element in psychological health. <https://www.crcpress.com/Guidebook-on-Helping-Persons-with-Mental-Retardation-Mourn/Kauffman/p/book/9780895033857>

## RESOURCES SPECIFIC TO PLANNING FOR THE DEATH OF A PWD OR THE DEATH OF SOMEONE A PWD LOVES

- **Caring at the End of Life**  
<https://www.aaid.org/news-policy/policy/position-statements/caring-at-the-end-of-life>
- **Palliative Care and Intellectual Disabilities**  
<http://www.intellectualdisability.info/physical-health/articles/cancer,-palliative-care-and-intellectual-disabilities>
- **Talking End of Life (TEL) with People with Intellectual Disability**  
<https://www.caresearch.com.au/TEL/>
- **People Planning Ahead: A Guide to Communicating Healthcare and End-of-Life Wishes** is a planning guide that helps families as well as professionals in developmental disability, geriatric care, and social work develop healthcare and end-of-life care plans in a way that is respectful and person centered. <https://www.amazon.com/People-Planning-Ahead-Community-Healthcare/dp/0940898985>
- **End of Life Care for Children and Adults with Intellectual and Developmental Disabilities** offers chapters on historical and legal aspects of care for those with intellectual and developmental disabilities; medical conditions and their treatment; ethical concerns; social, emotional, and spiritual considerations; and a listing of available supports and resources. <https://www.aaidjournals.org/doi/full/10.1352/1934-9556-49.5.407>
- **Thinking Ahead: My Way, My, Choice, My Life at the End** is a workbook originally created by California advocates with developmental disabilities who wanted to share their experiences and ideas about the importance of making end-of-life decisions. It was made possible by a wellness grant through the California Department of Developmental Services. CDDS gave the Texas Health and Human Services Commission permission to modify and issue this edition of the workbook for use in Texas. <https://hhs.texas.gov/sites/default/files/documents/doing-business-with-hhs/provider-portal/QMP/ThinkingAheadWorkbook.pdf>
- **End of Life Care: Bridging Disability and Aging with Person-Centered Care** features 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. <https://www.biblio.com/book/end-life-care-bridging-disability-aging/d/1185270628>
- **Caring for People with Learning Disabilities Who Are Dying** addresses the issues of power of attorney, walking with families in difficult times, circles of support around individuals who are seriously ill and palliative care. [http://www.aging-and-disability.org/en/complex\\_palliative\\_care](http://www.aging-and-disability.org/en/complex_palliative_care)



Preparation of this document was supported by the NJ Department of Human Services,  
Division of Developmental Disabilities (Contract #04ME20C)

April, 2020

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