



RESOURCES

Intellectual/Developmental Disabilities and Grief, Death, & Dying

A compilation of articles, books, and blogs to support people with intellectual and developmental disabilities as they grieve losses or prepare for their own death



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The Boggs Center
on Disability and Human Development

Robert Wood Johnson Medical School

Experiences of Grief with I/DD

"Dealing with Changes, Grief, and Loss" shares first-person accounts from people with disabilities about their experiences with death and grief. <https://www.youtube.com/watch?v=0GrFMkLrDv8>

"Bereavement In The Lives Of People With Intellectual Disabilities" describes ways support people inadvertently prevent an individual with I/DD from engaging with grief, and why this is harmful. <https://www.intellectualdisability.info/life-stages/articles/bereavement-in-the-lives-of-people-with-intellectual-disabilities>

"Making Sense of Death and Autism" in a NY Times Parenting Blog describes one autistic young adult's expressions of grief. <https://parenting.blogs.nytimes.com/2010/11/04/making-sense-of-death-and-autism/>

Resources for Supporting a Grieving Person with I/DD

"Managing Grief Better: People With Intellectual Disabilities" describes 9 areas of support caregivers and providers can offer to a grieving person with I/DD.

<https://www.intellectualdisability.info/mental-health/articles/managing-grief-better-people-with-intellectual-disabilities>

"How to Talk to Someone with an Intellectual Disability about Death, Even if You Aren't Sure You Should" debunks common misconceptions and normalizes experiences and expressions of grief in people with I/DD. <https://rosereif.com/talk-to-someone-with-intellectual-disability-about-death/>

"Supporting Somebody with an Intellectual Disability Through Grief" identifies common obstacles caregivers and providers face in supporting grieving people with I/DD and links to additional resources.

<https://www.funeralguide.co.uk/help-resources/bereavement-support/helping-the-bereaved/supporting-someone-with-a-learning-disability-through-grief>

"Supporting People with Disabilities Coping with Grief and Loss" is a booklet designed both for people with I/DD and their caregivers to normalize grief and provide guidance in the grieving process.

https://www.anglicarewa.org.au/docs/default-source/get-help/mental-health-services/care-basket/supporting-people-with-disabilities-grief-loss---scope.pdf?sfvrsn=9a8a96b2_2

"Helping People with Developmental Disabilities Mourn: Practical Rituals for Caregivers" focuses on creating mourning rituals for people with developmental disabilities. This guide offers examples of specific rituals and techniques for 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>

"How to Talk to People with Learning Disabilities about Death (and Why You Should)" is a list of simple tips for including people with I/DD in conversations about rituals around death.

<https://www.mariecurie.org.uk/talkabout/articles/how-to-talk-people-with-learning-disabilities-and-why-you-should/263626>

"Lessons in Grief and Death: Supporting People with Developmental Disabilities in the Healing Process" describes the grief counseling process, offers activities—including art, music, and drama—that can be used to help a person through the grief process, and shares stories of real individuals coping with a variety of deaths and losses.

<https://cherryhillhightide.com/product/lessons-in-grief-death/>

Hospice Foundation Self-Study DVD Supporting Individuals with Intellectual and Developmental Disabilities Through Serious Illness, Grief and Loss addresses ethical, medical management, and psychosocial issues for individuals with intellectual and developmental disabilities facing death, grief, and loss. This two-hour educational resource focuses on the critical challenges of providing and accessing optimal end-of-life care and bereavement support for this population. <https://hospicefoundation.org/HFA-Products/Supporting-IDD-DVD-Self-Study>

Pathfinders for Autism's "PFA Tips: Death and Grieving" includes suggestions for explaining death, funerals, and loss to children 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 Autism & Grief Project offers numerous resources for autistic people, caregivers, and providers related to death and grief. <https://www.autismandgrief.org/>

"Coping with Grief in the Lives of People with Intellectual Disabilities and/or Autism" is a half-hour webinar offering guidelines for caregivers and providers supporting people with I/DD in experiences of grief with consideration for cultural and faith practices. <https://www.youtube.com/watch?v=ZZr0SyfVcAM>

End-of-Life Planning and I/DD

"Palliative Care and Intellectual Disabilities" addresses healthcare inequalities for people with I/DD at the end of life and offers guidelines for caregivers and providers.

<https://www.intellectualdisability.info/physical-health/articles/cancer,-palliative-care-and-intellectual-disabilities>

Talking End of Life (TEL) with People with Intellectual Disability is an online educational resource covering a variety of topics related to end-of-life care, death, and grief for people with I/DD. <https://www.caresearch.com.au/TEL/>

"Thinking Ahead: My Way, My Choice, My Life at the End" is a workbook created by advocates with developmental disabilities who wanted to share their experiences and ideas about the importance of making end-of-life decisions.

<https://selfadvocacyinfo.org/resource/thinking-ahead-my-life-my-choice-my-life-at-the-end/>

End of Life Care: Bridging Disability and Aging with Person-Centered Care features articles and resources related to both developmental disabilities and Alzheimer's.

<https://www.biblio.com/book/end-life-care-bridging-disability-aging/d/1185270628>

"Responding to Complex Needs" addresses issues of power of attorney, walking with families in difficult times, circles of support around individuals who are seriously ill, and palliative care.

https://aging-and-disability.org/en/complex_palliative_care

"My Plan for a Good Life, Right to the End" is a template that individuals with I/DD and their support people can use as a guide for advanced care planning. <https://www.understandable.org.nz/advance-care-planning>

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