

These resources are being provided for Persons with Intellectual and Developmental Disabilities (PWIDD), their Families and their Healthcare Providers to connect them with tools for understanding the death and dying process and to supply strategies for coping with their grief.

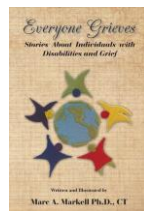
Although the outward expression of someone's grief may be difficult to recognize, the need for their grief to be acknowledged and supported is universal.

Books

Everyone Grieves

Stories about Individuals with Disabilities and Grief

Marc A. Markell, (2013)



Something Very Sad Happened

A Toddler's Guide to Understanding Death

Bonnie Zucker (2016)



Helping People with Developmental Disabilities Mourn

Practical rituals for Caregivers

Marc A. Markell (2005)



What Happens When a Loved One Dies

Our First Talk about Death

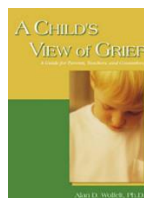
Dr. Jillian Roberts (2016)



Picking up the Pieces

A Child's View of Grief

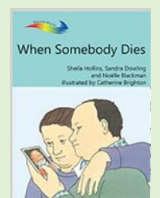
Alan D. Wolfelt (1990)



*When Someone Dies

Noelle Blackman; Sandra Dowling; Sheila Hollins (2018)

<https://booksbeyondwords.co.uk/bookshop/paperbacks/when-somebody-dies>



Saying Goodbye to Uncle Joe

What to Expect When Someone You Love Dies

Nancy Loewen (2011)



**These books were recommended by L'Arche Canada and are in print and e-book version. There is a cost to order either version, since they ship from Ireland.*

Note: *Hospice Waterloo Region and Hospice Wellington have a list of books to lend out in their Libraries. Please check either Hospice to see if they have the resources you are looking for.*

Applications

Calm (meditation/sleep)

<https://www.calm.com/>

Headspace (meditation)

<https://www.headspace.com/>

The Mindfulness App

<https://www.themindfulnessapp.com/>

Insight Timer (meditation/sleep)

<https://insighttimer.com/>

Grief Works: self care and love

<https://apps.apple.com/gb/app/grief-works-self-care-love/id1558867513>

Movies/Videos

Movies

Coco

<https://www.imdb.com/title/tt2380307/>

Mr. Magorium's Wonder Emporium

<https://www.imdb.com/title/tt0457419/>

Up

<https://www.imdb.com/title/tt1049413/>

We Bought a Zoo

<https://www.imdb.com/title/tt1389137/>

Videos

How to Talk about Death and Grief with Someone who has a Learning Disability

<https://www.youtube.com/watch?v=nEcLPE5ceIA>

My Grief Assist

<https://www.mygriefassist.com.au/inspiration-resources/movies/>

Supporting People with Learning Disabilities in Bereavement (Webinar)

<https://www.youtube.com/watch?v=1Z4luRcbJJE>

What's Your Grief?

<https://whatsyourgrief.com/64-movies-about-grief-and-loss/>

Websites

<p>Aging and Disability</p> <p>Grieving http://www.aging-and-disability.org/en/grieving</p> <p>Grieving in the Context of a Community of Differently-abled People http://www.aging-and-disability.org/documents/grieving_in_the_context_of_a_community_of_differently-abled_people.pdf</p>	<p>This website looks at ways that people can support one another through the grieving process. It gives particular attention to the experience of grieving in the context of a community of 'differently-abled' individuals.</p> <p>A case study of a L'Aarce community for supporting adults with developmental disabilities in grief.</p>
<p>Autism-Specific Resources</p> <p>Autism Speaks https://www.autismspeaks.org/grief-and-bereavement-resources</p> <p>Grief and Autism https://www.autismandgrief.org/wp-content/uploads/2021/12/Autism-Grief-Grief-and-Autism-2.pdf</p> <p>Autism Now https://autismnow.org/blog/bereavement-and-autism-a-universal-experience-with-unique-challenges/</p>	<p>Autism Specific Resources</p>
<p>Cake</p> <p>12 Grief Activity Ideas for Adults & Children https://www.joincake.com/blog/grief-and-loss-activities/</p>	<p>Some activities that they can take part in will help them to better understand death and how they're feeling as a result of having lost their loved one.</p>
<p>ConnectAbility</p> <p>Grief and Bereavement https://connectability.ca/2015/03/09/grief-and-bereavement-2/</p>	<p>This website provides a mix of grief resources and supports for persons with intellectual and developmental disabilities and their families.</p>
<p>Down Syndrome Society of Greater St. Louis</p> <p>Grief Packet https://dsagsl.org/wp-content/uploads/2019/02/Grief-Packet.pdf</p>	<p>The first section of this resource speaks directly to people with developmental disabilities, and the second provides recommendations to care partners/the person's support network</p>

<p>Indiana Institute on Disability and Community</p> <p>When Someone Dies https://www.iidc.indiana.edu/irca/articles/assets/when_someonedies.pdf</p> <p>Going to a Visitation https://www.iidc.indiana.edu/irca/articles/assets/goingt_oavisitation.pdf</p> <p>Going to a Funeral https://www.iidc.indiana.edu/irca/articles/assets/goingt_oafuneral.pdf</p> <p>Going to the Cemetery https://www.iidc.indiana.edu/irca/articles/assets/goingt_othecemetery.pdf</p>	<p>Social Stories Explaining Death and Grieving Rituals (although not all forms are represented)</p>
<p>Intellectual Disability and Health</p> <p>Managing Grief Better: People With Intellectual Disabilities http://www.intellectualdisability.info/mental-health/articles/managing-grief-better-people-with-intellectual-disabilities#:~:text=Managing%20Grief%20Better%3A%20People%20With%20Intellectual%20Disabilities%201,persist%201.%20Be%20honest%2C%20include%20and%20involve%20</p>	<p>Article</p>
<p>Kids Grief https://kidsgrief.ca</p>	<p>This website contains a mix of different grief resources and education modules for parents and educators to help support children during their grieving process.</p>
<p>Living and Dying with Dignity</p> <p>Best Practice Guide https://www.virtualhospice.ca/Assets/Living-and-dying-with-dignity-the-best-practice-guide-to-endoflife-care-for-people-with-a-learning-disability%20-%202008_20181016111240.pdf</p>	<p>This is a best practice guide to end of life care for people with a developmental disability (chapter 8 is specific to grief and bereavement).</p>
<p>MAID Family Support Society https://maidfamilysupport.ca/</p>	<p>This is a peer-to-peer resource for individuals who are experiencing grief of a loved who accessed Medical Assistance in Dying (MAID) and offers various supports for this type of grief.</p>

<p>My Grief https://mygrief.ca</p>	<p>This website contains a mix of different grief resources and education modules for adults wanting to understand more about grief and feel supported through their grieving process.</p>
<p>Palliative Care for People with Learning Disabilities Network Resources https://www.pcpld.org/links-and-resources/</p>	<p>Website with information and training materials for care givers of people with learning disabilities on how to break bad news.</p>
<p>Refuge in Grief Grief Support That Doesn't Suck- Megan Devine https://refugeingrief.com/</p>	<p>Podcast with Megan Devine – book “It’s ok that you’re not ok”</p>
<p>What’s Your Grief https://whatsyourgrief.com</p>	<p>This website’s goal is to create a community that provides hope, creative expression, support, and education to anyone wishing to understand the complicated experience of life after loss.</p>
<p>UK Based Resources HSC Bereavement Network https://hscbereavementnetwork.hscni.net/wp-content/uploads/2015/05/96885-NHSCT-Client-Booklet-2016.pdf Keele University https://aldhc.keele.ac.uk/repos/Presentations/Understanding%20Loss%20and%20Bereavement%20PDF.pdf Down Syndrome Scotland https://www.dsscotland.org.uk/wp-content/uploads/2019/05/DSS_LETS-TALK-ABOUT-DEATH_WEB.pdf Mencap https://www.mencap.org.uk/advice-and-support/wellbeing/dealing-bereavement</p>	<p>UK Based Resources</p>

Podcasts

Terrible, Thanks For Asking
<https://www.ttfa.org/about>

Multiple bereavements and being honest rather than pretending like everything is okay.

Griefcast
<https://cariadlloyd.com/griefcast>

Guests talk about their experience with grief; the honest, the raw, the heartbreaking, the sometimes funny moments.

Grief Out Loud

<https://www.dougy.org/news-media/podcasts>

The Mindfulness and Grief Podcast

<https://mindfulnessandgrief.com/grief-podcast/>

All There Is with Anderson Cooper

<https://www.cnn.com/audio/podcasts/all-there-is-with-anderson-cooper>

This podcast from the Dougy Center wants you to talk about your grief out loud, in public, and they're here to support you while you do it.

Stang offers compassionate advice and tips for a mindful approach to grief and the complex emotions that come with it.

Cooper begins a series of emotional and moving conversations about the people we lose, the things they leave behind, and how to live after they're gone—with loss, laughter, and love.

Other

Activity Book

Finding your own way to grieve: A creative Activity workbook for kids and teens on the Autism Spectrum by Karla Helbert (2012) (can be purchased on Amazon)

Deck of Cards

The Grief Companion: A Supportive Guide to Navigating Grief. By Ngaio Pa (can be purchased on Amazon)

Colouring Book

Coping with Grief: An Adult Colouring Book for Grief, Loss and Healing (can be purchased on Amazon)

Journal

How to carry what can't be fixed- by Megan Devine (can be purchased on Amazon)

Legacy Activities

- ❖ **Pieces of You in my Heart** – Hospice Wellington (contact info@hospicewellington.org)
- ❖ **Legacy of Love** – Hospice Waterloo Region (contact: intake@hospicewaterloo.ca)

Note: These are samples of resources that are available. You will need to find ones that are appropriate for you or your PWIDD. Please speak to a Hospice Waterloo or Hospice Wellington staff member for other resources available. Each Residence (Hospice Waterloo and Hospice Wellington) have Resource Toolkits on hand.

For Health Care Providers

- ❖ Aging & Disability Grieving Resources
<http://www.aging-and-disability.org/en/grieving>
- ❖ ConnectABILITY Grief & Bereavements Resources
<https://connectability.ca/2015/03/09/grief-and-bereavement-2/>
- ❖ Light House Beacon Podcast
Episode15: Children's grief support for individuals living with intellectual and developmental disabilities a clinical perspective
<https://rshami.podbean.com/e/episode-15-children-s-grief-support-for-individuals-living-with-intellectual-and-developmental-disabilities-a-clinical-perspective/>
- ❖ PCPLD Network
Supporting people with learning disabilities in Bereavement webinar (Video: 75 min)
<https://youtu.be/1Z4luRcbJJE>
- ❖ Irene Tuffrey-Wijne
Professor of Intellectual Disability and Palliative Care Website
<http://www.tuffrey-wijne.com/>

❖ SCOPE

Supporting People with Disabilities Coping with Grief & loss: An easy-to-read booklet (2007)
<https://dsagsl.org/wp-content/uploads/2019/02/Grief-Packet.pdf>

Other Agency Resources

Local and Provincial/National Associations Supporting people with IDD

Adults in Motion (AIM)

<https://adultsinmotion.org/>

Autism Ontario

<https://www.autismontario.com/>

Bridges to Belonging

<https://www.bridgestobelonging.ca/>

Extend-a-Family Waterloo Region

<https://eafwr.on.ca/>

Kerry's Place

<https://www.kerrysplace.org/>

OPADD (Ontario Partnership on Aging & Developmental disabilities)

<https://reena.org/?s=OPADD>

L'Arche Canada

<https://www.larche.ca/>

Nightingale Centre

www.nightingalecentre.org

Waterloo Region Family Network

<https://wrfn.info/>

Waterloo Wellington Down Syndrome Society

<https://www.wwdss.ca/>

CRPADD (Central Region Partnership on Aging & Developmental Disabilities)

<https://pclkw.org/crpadd-resources/>

These resources will be updated annually on our websites:


Hospice
Waterloo Region
hospicewaterloo.ca
519-743-4114


Hospice
Wellington™
YOUR STORY MATTERS
hospicewellington.org
519-836-3921