Robert Wood Johnson Medical School The Boggs Center on Developmental Disabilities

New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service

COVID-19: Grieving Lives Lost and Loss of Lives

Margaret T. Gilbride, JD, CT <u>Margaret.Gilbride@rutgers.edu</u> Arc NJ Webinar 5/17/22 GRIEVING THE LOST

Rutgers, The State University of New Jersey

Statistics

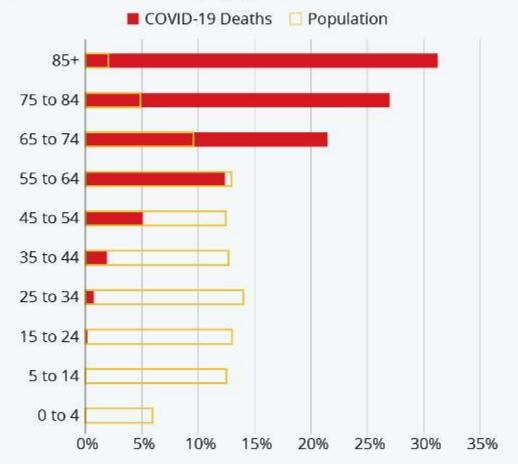
- 641,860 over 60 in 2000
- 1,200,000 over 60 by 2030 Heller, T. (2010)
- First generation
 - -To live this long
 - -To outlive their parents and siblings



COVID Impact By Age

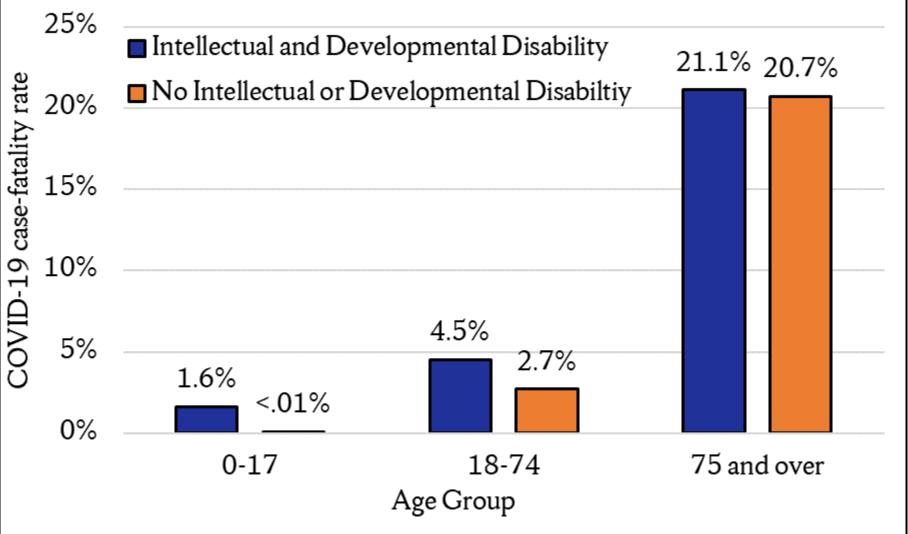
The Pandemic's Disproportionate Toll on the Elderly

Distribution of COVID-19 deaths and total population in the United States by age group*



^{*} COVID deaths as of Dec. 2, 2020; population estimates as of 2019 Sources: CDC, U.S. Census Bureau

COVID and IDD



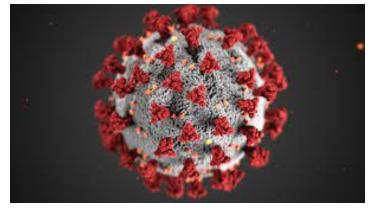
TriNex COVID-19 Research Network; includes COVID-19 deaths through May 14, 2020. IDD includes intellectual disability, cerebral palsy, Down syndrome, as well as other rarer types of develomental disability.





Where We Have Been

- Lucille Escralew in "Transitioning to a post-COVID World: Clinical and Behavioral Considerations" May 3, 2022



Enforced Closures

FGERS

- Social Isolation and social disconnection
- Disruption to daily routines
- Loss of family, co-workers, support staff
- Interruption in services
- Restricted opportunities for learning, work, leisure and meaningful activity
- Financial disruption

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People experience many (non-death) losses.



Non-death losses

Health*

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Relationships*



- Trust
- Dreams
- obs COVID
- Mobility*

- **Status**
- Memory*
- Possessions*
- Money*

- **Red** = Abstract * = Hidden
 - Abstractions

- SecurityOVID
- Sense of self
- Pet*
 - Lost
 - Allergy
 - Relocation



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Cumulative Effect

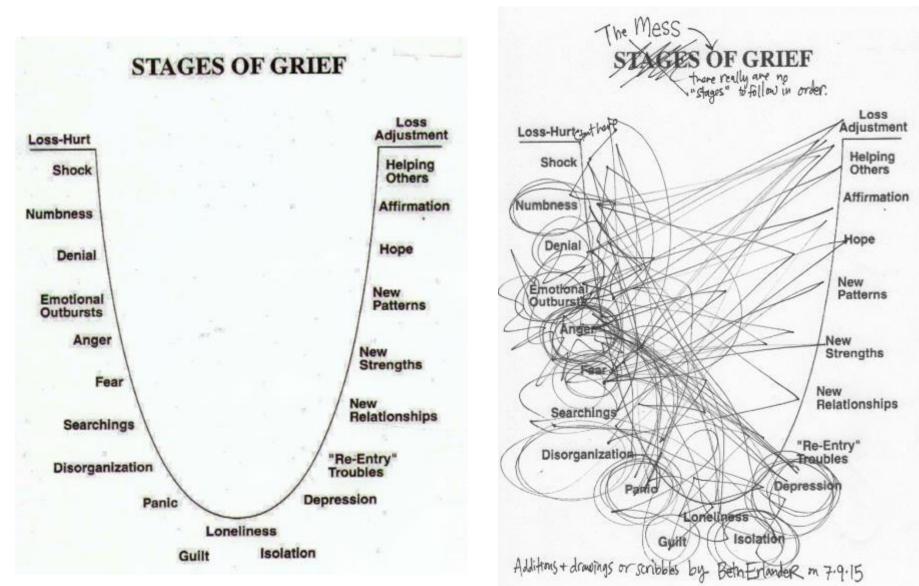


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The Truth

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The Myth



- Increased compulsivity
- Injury to self/others
- Self-oriented

- Magical thinking
- Withdrawal/Clinging
- Somatic Distress
- Running away
- Perseverating
- Competing with others' grief

Accumulation Witnessed

Having a very bad reputation...





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The paradigm for loss, grief and mourning is DEATH.

- All losses are deaths.
- Deaths demand to be grieved.
- Grief's face is mourning.
- Mourning is individual and communal.



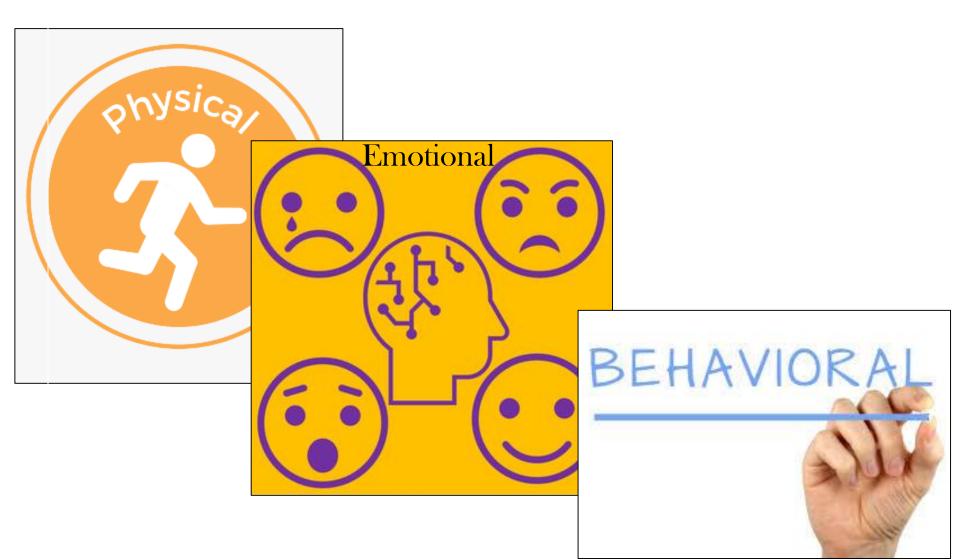


Typical reactions (grief) people have to loss.





Grief Reactions (NORMAL)



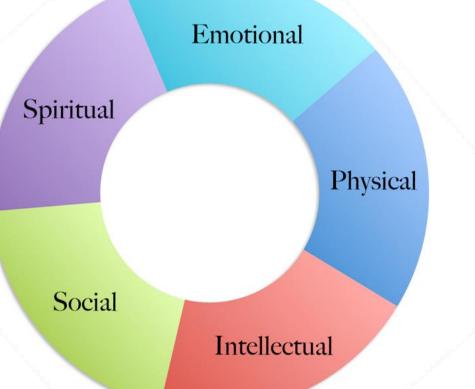
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Grief Reactions

- Physical
- Cognitive
- Emotional
- Behavioral
- Spiritual
- Social

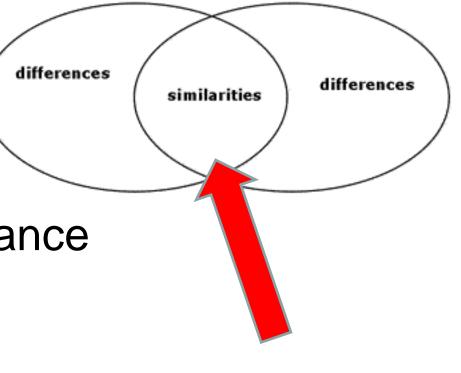




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Similarities of Loss and Grief

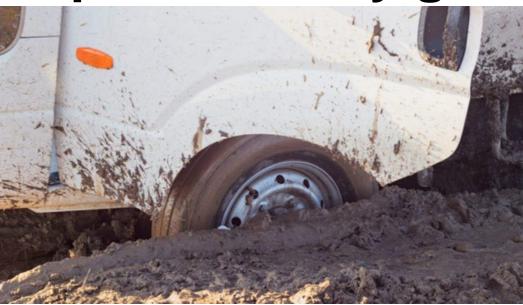
- Every loss = grief
- No permanent avoidance
- No "right way"
- No time table
- Every loss is a multiple loss
 Secondary losses
- Old grief comingles with new





Four steps to healthy grieving

-Worden



- Accept the Reality of Loss
- Experience the Pain of Grief
- Adjust to Life Without
- Withdraw and Reinvest Energies





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• Frequent

- Concurrent
- Language
- Grief "drama"
- Socially unsupported
- Lacking resources
- Uncertainly set

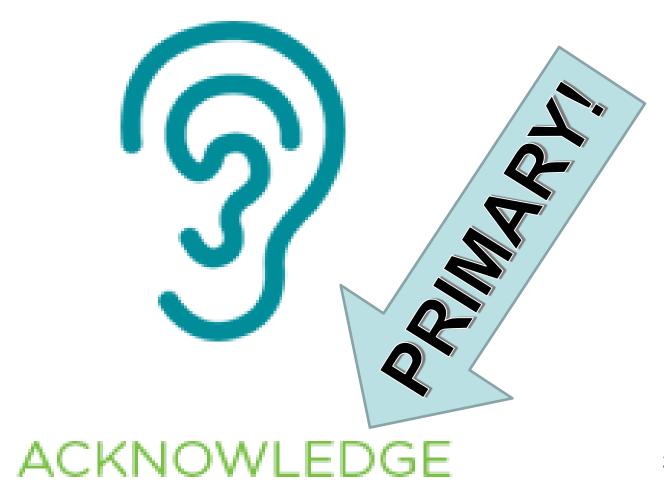
Disenfranchised

Left out

- Misplaced benevolence
- Assumptions
 - ability to understand
 - ability to feel/ experience



Strategies to help Navigate



More Strategies

- Be honest: include, involve, prepare
- Use concrete language
- Listen (let people tell their stories)
- Actively seek out nonverbal rituals
- Respect photos and other mementos
- Minimize change
- Avoid assessment of skills
- Support anniversaries and "events"



Planning is strategy

- Do a loss assessment
 - -The story

- -The reactions
- -The adaptations
- Develop a written plan CENTEREL PLANNING
 - -The current reality
 - -The predictable future
 - -The unforeseen occurrences

Four steps to healthy grieving -Worden

Accept the Reality of Loss

- concrete illustrations of info; wake, funeral, disposition; video/audiotape; "gift"
- Experience the Pain of Grief
 - be; model; feeling aids; arts; messages; gap fill
- Adjust to Life Without
 - the arts; photos, boxes, etc.; who now?; rituals
- Withdraw and Reinvest Energies
 - plant; contribute; represent; create; participate







Madman Spanning The Brink of Disaster By The Grace of A wonderful Ignorance. RESPONDING TO GRIEF REACTIONS

OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

ADAPTED FROM ROBERT L. MORASKY, PHD

RITUALIZING GRIEF

WITH PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

HELPING PEOPLE

WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES PROCESS GRIEF

RESOURCES

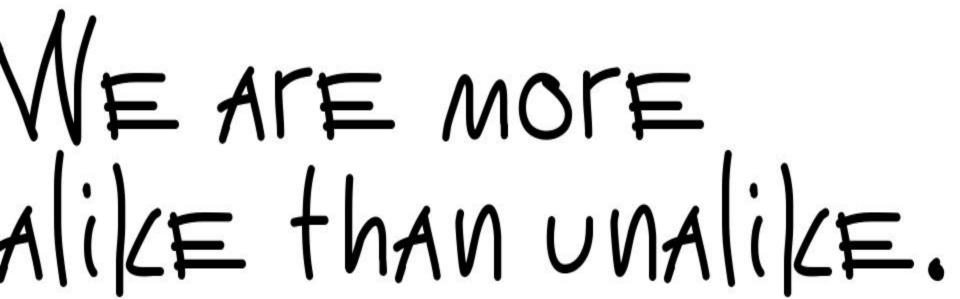
INTELLECTUAL/DEVELOPMENTAL DISABILITIES AND GRIEF, DEATH, & DYING

Spanning the Brink of Disaster by the Grace of a Wonderful Ignorance



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An Ultimate Truth



Lives at home with parent

- Same house for life
 - Neighborhood
 - Neighbors

- Faith community
- Adult provider
 - School
 - Day services
- Circle of friends



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Concurrent Losses



- Parent
 - Home
- Neighborhood
 - Neighbors
 - Lost Faith Community
 - Lost Provider
 Agency
- Lost Circle of friends

Secondary Losses

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Lost Parent

 Love, affection, favorite foods, social network, routines, grounding, world

Lost Home

 Pet, neighborhood, safety, independence, privacy, possessions, freedom, the familiar

Lost Faith Community

 Valued role, being known, the familiar, friends, support system, grief support



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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
 <u>http://www.intellectualdisability.info/mental-health/articles/managing-grief-better-people-with-intellectual-disabilities</u>
- Bereavement In The Lives Of People With Intellectual Disabilities
 <u>http://www.intellectualdisability.info/life-stages/articles/bereavement-in-the-lives-of-people-with-intellectual-disabilities</u>
- How to Talk to Someone with an Intellectual Disability about Death, Even if You Aren't Sure You Should
- <u>http://reifpsychservices.com/talk-to-someone-with-intellectual-disability-about-death/</u>
 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 <u>http://citeseerx.ist.psu.edu/viewdoc/download?</u> <u>doi=10.1.1.604.9954&rep=rep1&type=pdf</u>
- 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. <u>https://www.amazon.com/Helping-People-Developmental-Disabilities-Mourn/dp/1879651467</u>
- 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. <u>https://www.cavershambooksellers.com/search/1896230261</u>
- 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. <u>https://barbaraglanz.com/products/books/what-can-i-do-ideas-to-help-those-who-have-experienced-loss/</u>
- 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. <u>https://cherryhillhightide.com/product/lessons-in-grief-death/</u>
- 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 endof-life care and bereavement support for this population.

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.

 <u>https://pathfindersforautism.org/articles/home/parent-tips-death-and-grieving/</u>
 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.: <u>http://rcgnc.com/WellnesLibrary/DD-MR%20Specific%20Tools/The%20Geese%20and%</u>

- <u>http://rcgnc.com/WellnesLibrary/DD-MR%20Specific%20Tools/The%20Geese%20and%</u> <u>20Chocalete%20PB%20Ice%20Cream.pdf</u> Helping Adults with Mental Retardation Grieve a Death Loss is a guide designed to belo
- 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. <u>https://www.amazon.com/Helping-Adults-Mental-Retardation-Grieve/dp/1560327685</u>
- 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. <u>https://www.redcross.org/virtual-family-assistancecenter/nj-family-assistance-center.html</u>

 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. <u>https://www.crcpress.com/Guidebook-on-Helping-Persons-with-Mental- Retardation-Mourn/Kauffman/p/book/9780895033857</u>

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

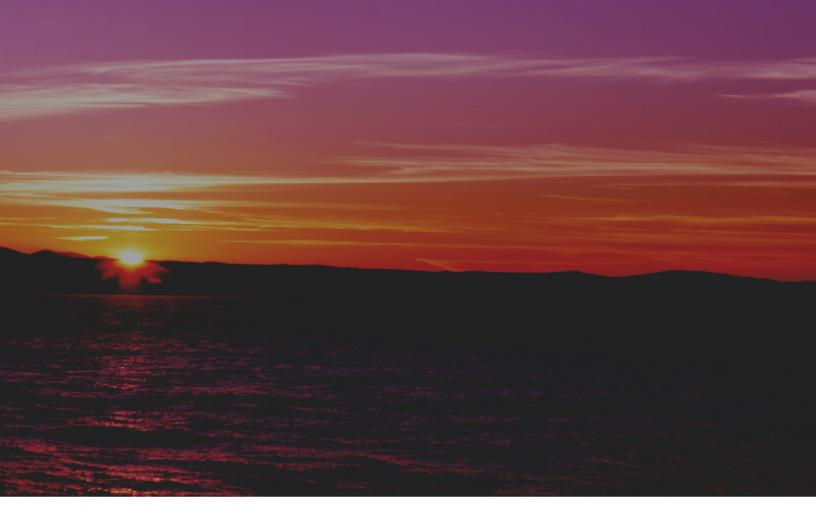
- Caring at the End of Life
 <u>https://www.aaidd.org/news-policy/policy/position-statements/caring-at-the-end-of-life</u>
- Palliative Care and Intellectual Disabilities <u>http://www.intellectualdisability.info/physical-health/articles/cancer,-palliative-care-and-intellectual-disabilities</u>
- Talking End of Life (TEL) with People with Intellectual Disability <u>https://www.caresearch.com.au/TEL/</u>
- 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. <u>https://www.amazon.com/People-Planning-Ahead-</u> <u>Community-Healthcare/dp/0940898985</u>
- 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. <u>https://www.aaiddjournals.org/doi/full/10.1352/1934-9556-49.5.407</u>

• 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://bbs.texas.gov/sites/default/files/documents/doing-business-with-bbs/provider-

https://hhs.texas.gov/sites/default/files/documents/doing-business-with-hhs/providerportal/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. <u>https://www.biblio.com/book/end-life-care-bridging-disability-aging/d/1185270628</u>
- 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



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April, 2020

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HELPING PEOPLE with intellectual and developmental disabilities PROCESS GRIEF

Professionals in the field of grief and loss suggest direct support professionals become familiar with the ways grief and loss impact people with intellectual and developmental disabilities (IDD). The accumulation of losses over a lifespan can cause serious health concerns if unacknowledged/unsupported. The ideas below are stated in terms of helping individuals process the death of a person they valued but can be adapted to assist in processing any significant experience of loss or change. What is critical is that people have their loss and accompanying feelings acknowledged and be provided opportunities to experience the feelings and move, at their own pace, to their "new normal."

- Use pictures (magazines/computer searches) to allow a person to concretely depict feelings, emotions, etc. about the deceased
- Engage in drawing activities to convey events, feelings, emotions, etc. about the deceased
- Create together a memory box of items that remind the individual of the deceased (don't forget items with smells—lotions, soaps, spices, coffee)
- Make a photo album or scrapbook about the deceased or times spent with the deceased
- Take a trip together to the graveside or previous home or former workplace or place of significance shared with the deceased
- Have the individual help plan the memorial or have a role in the memorial or goodbye celebration(s)
- Do something together that the person used to do with the deceased or do something that is in honor or in tribute of the deceased
- Use YouTube or TV shows/movies that portray people grieving to help illustrate and normalize the experience and its feelings
- Designate a "space" to keep a memorial item(s)—this may be used in conjunction with a calendar that marks significant dates
- Use pictures/photos to tell /share stories about the deceased
- Use colors to symbolize feelings
- Help the person illustrate (pictures/drawings/etc.) what they miss about the person



- Create a "remember journal" that can be added to over time
- Brainstorm ways to celebrate the deceased person's life or the time enjoyed with him/her at a significant place(s) using an object of meaning and/or symbolism
- Write letters to the deceased and bury them/burn them/etc.
- Set a place at the table, set a photo visibly in that place, name the person in a "memory share" before the meal for a memorial and/or a holiday remembrance
- Have a ceremony, show photos, tell stories, share what you'll miss about the deceased and say good bye
- Take an hour each month, on the anniversary day of a death to handle objects, look at photos, or to write about the loss experience
- Plant a tree or flowers to honor the deceased or the occasion of a loss
- <u>https://www.pinterest.ca/kmatitich/grief-activities/</u> for over 300 activities from which to choose

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RESPONDING TO GRIEF REACTIONS

OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

ADAPTED FROM ROBERT L. MORASKY, PHD

For many reasons, people with intellectual and developmental disabilities (IDD) are often not included in the usual conversations, cultural rituals, and other means of personal and/or communal acknowledgement of loss and grief. As a result of not being included, their grief reactions can be complicated and/or prolonged. Additionally, the language of grief for people with IDD, whether or not they are verbal by nature, is primarily behavioral. In order to help people process their grief, we first need to recognize it as the source of the thoughts, feelings, and/or fears which their actions convey. Below is a table designed to help you identify specific situations grievers with IDD may experience and behavioral communications that may be grief related. For each situation or communication there is a strategy to employ that may promote healing.

SITUATION OR BEHAVIORAL COMMUNICATION

The individual was not able to attend the wake or funeral or ethnic/cultural equivalent or did not comprehend the meaning of the event(s)

You are not certain the individual understands "death" or think s/he may have a simplified notion of it (e.g., not realize its permanence). Given his/her level of understanding s/he may be confused if people seem hesitant to talk about it

STRATEGIES TO ASSIST

Help the person conduct a goodbye ritual that is concrete and personally meaningful. A ritual that acknowledges the person's loss and allows them to say goodbye

Describe death concretely. Avoid phrases like "passed on," "went to sleep," "no longer with us." Do not avoid talking about "the what" and "the how" within reason. Use items/ experiences to teach the body "no longer works," "can't be fixed," "the person won't come back."

SITUATION OR BEHAVIORAL COMMUNICATION

The individual may be feeling emotional pain that is unlike anything s/he has ever experienced and s/he may think/fear the pain will never go away but not have the words to express that fear

The individual believes/fears that other people s/he knows are now going to die

The individual may not know how to ask for information about what happened (or what will happen). Even the idea of asking for information may not occur to him/her

In their grief, people may ask questions repeatedly. The same question may be asked often in a short period of time

The individual appears to be searching for the deceased. The search can be actual (looking in places) or virtual (talking about the person, asking for the person)The individual says s/he saw the deceased person. This may have occurred in a dream or in his/her imagination, but the person was seen and was real to her/him

Shortly after a known death or significant loss, an individual begins to behave differently than s/he did prior to the event

STRATEGIES TO ASSIST

Acknowledge the pain and assure the person that s/he will not always feel it so strongly. Be a reflective listener to verbal and non-verbal communication. Avoid saying, "I know how you feel..." "You have to be grown up about this..." "What you need is..." "You'd feel worse if...." It can help if you name the feeling: "You feel sad. You feel mad." Use of a feelings chart may be helpful.

Explain others are not going to die just because one did. Point out that people continue to be around. Use an example if available (i.e. "It's like when one of the fish in the tank dies, the others keep living.")

Help the person to ask questions: "Do you want to know about...?" and encourage them to do so. Notice when a person is trying to get information from you

Keep answering the questions. It is the feelings of grief and not a lack of information that is causing the repetition

Support the individual in the search but again explain the "foreverness" of death. Acknowledge the loss. You may want to ritualize another goodbye. Anniversaries, holidays, seasons can trigger searching

Reflect back to the person that her/his actions are a way of expressing the hurt and pain of grief: "You threw your clothes all over your room and broke those things because...

SITUATION OR BEHAVIORAL COMMUNICATION

STRATEGIES TO ASSIST

...(cont'd) you're missing _____. I know you're hurting inside(touch your own heart to show hurt there)." Suggest doing one of the other grief processing activities

Listen to the fears. Don't contradict or deny them, just acknowledge them. If fear persists over time, or interferes with life activities, refer for counseling

Use deep breathing and other relaxation techniques

Know that grief comes and goes and that there are numerous triggers for it. Respond to each cycle of grief in the same way you did the previous cycle. Each one will need healing as much as the one(s) before it

Recognize that rituals provide security. Be aware that a ritual of comfort can arise out of any activity (taking a coffee break, looking at a photo album, etc.). Help the person maintain and practice the rituals they select

Important "grief-triggering days" need to be anticipated and supported. Help the Individual carry out a memorial tribute/ritual to acknowledge the significance of the day

Give him/her choices about how to memorialize the person and express his/her feelings. The choices may be expressed in action rather than words (pictures, dance, volunteering). Smell and taste are tied strongly to memory and are important tools in memorialization

Grief causes fear

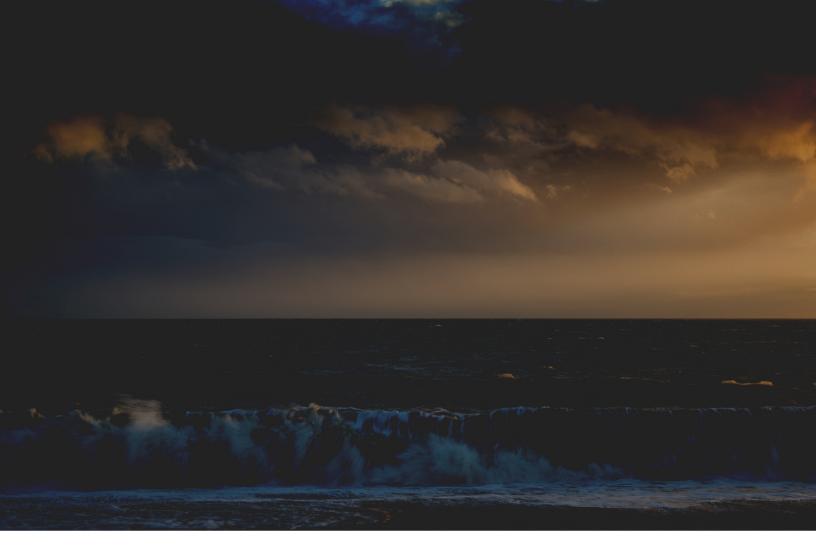
Grief causes anxiety

A new experience (personal or the witnessing of someone else's loss) renews the individual's feelings of missing someone

There is an observed increase in ritualized behavior

Anniversary, holiday, birthday, etc.

The individual may want to remember the deceased in a special way



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RITUALIZING GRIEF WITH PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

When discussing person-centered thinking and practices, the topic of rituals often surfaces: the need to capture the rituals of relationship (e.g. I always have a cup of tea when I visit with Rose) and the rituals of comfort (I like classical music and a burning candle when I relax) important to an individual. Rituals motivate and move us. They help us define our families, build community, make transitions, and mark important life events. Through ritual we express our joy and sorrow. We do so alone, in private, and together, in relationship with others. In no circumstance is ritual more important than in acknowledging, experiencing, supporting, and healing the grief experienced because of the death of another. Mourning rituals are universal. There is such a wide variety held by different ethnicities, cultures, faith traditions and families, that they can even be contradictory. People perform mourning rituals in an effort to alleviate their grief - but do they work? The research of Francesca Gino and Michael I. Norton, first published on May 14, 2013 in Scientific American, showed that they do. What follows is a guide to planning a grief ritual and some suggestions for items or activities around which a ritual can be designed. These are rooted in neither cultural nor faith traditions and are not meant to replace either; they are meant merely to provide the opportunity to express personal and communal loss in a safe, symbolic, participatory and meaningful way.

HOW TO PLAN A RITUAL FOR PEOPLE WITH IDD

- Make the ritual concrete rather than abstract: because of the nature of their disability, people with IDD generally benefit from more concrete experiences that include activities or include the use of physical, representative items
- Use explicit directions, with few words. When possible, providing picture illustrations of the directions and/or modeling should be used
- Keep the ritual simple: rituals that are too complicated or open-ended may be confusing, frustrating and of little meaning
- It is important to maintain an element of symbolism—to have the activity done, or the object used, represent something beyond its literal meaning

TO MAKE RITUALS IMPACTFUL DESIGN THEM SO THE PERSON PARTICIPATES THROUGH SYMBOLIC GESTURE OR OBJECT

- Use Photos (of the deceased or from magazines/computer images in representation)
- Use Storytelling ("I remember when..." or "What I will miss the most about...")
- Use Memory Objects ("I brought this cup today because..." or "This reminds me of...")
- Use a Perennial plant or Tree ("Let's plant this tree in her memory and whenever we want to talk to her we can come here" or "Every time this plant flowers we will remember...")
- Use Drawing ("Draw what he meant to you" or "Color your paper heart with a color that shows how you feel right now.")
- Use Music ("Let's sing/play her favorite song.")
- Use Writing ("Write what you would say to him right now" or "Write one word about him.")
- Use Stones/Seashells/Tee shirts/Pottery/Modeling Clay for a keepsake ("Paint whatever you want in her memory on this" or "These playing cards were hers, each person take one.")
- Use Light (a candle that can bit lit on special days, a nightlight, etc.)
- Use the act of Burying an Object (personal item, goodbye notes, something symbolic of the deceased or of the feelings of the griever)
- Use Food (share a favorite dessert or favorite meal "in honor of")

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