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# End of Life, Loss, and Grief: Accompanying People with Intellectual Disabilities, their Families and Friends



# People with IDD and Grief: How things have changed!!

People were  
never told

Death was out  
of sight

"People with  
IDD don't  
express grief."

People did not  
know how to  
support people  
with IDD in grief.

Belief that grief  
support had to  
be  
"specialized."

Focus on  
"chronic grief"  
of parents



## In Older Institutional Systems of Care: Death an Indicator of

Loneliness and loss  
of connection

Injustice, no power,  
at hands of system,  
professionals,  
family

Abandonment

Family wounds

They usually did not participate in rituals of mourning. Why?

- Others being protective. (of whom?)
- "They would not understand."
- "They would get upset." Or "They would upset the funeral, etc."





# Now.....

- ▶ Live in a world full of losses. We see them every day. TV, staff changes, friends come and go, moves, etc.
- ▶ Recognition that unexpressed grief can act itself out.
- ▶ Society as a whole is not good with planning ahead or coping.
- ▶ Too often rely on "Bring in the professional (i.e. specialized) grief counselor."
- ▶ With COVID, huge awareness of the tragedy of isolation and loneliness.
- ▶ Not uniform, but people are much more connected than in the days of institutions
- ▶ If inclusion and belonging is key, why not here as well?



Is God in nature?  
 My Mom died. Who will watch my cats?  
 My Pop-pop died.  
 I miss my friends at Woodbine. I don't like to think about Woodbine.  
 I really, really miss them. What is cancer?  
 Where do people go when they die? I can't talk to my friend in Ancara?  
 Why does cancer kill a person? I'm sad. How can I see my friends from New Lisbon?  
 I need help to get there. I don't like to think about Woodbine.  
 My best friend doesn't live here anymore. I know I'll never be able to drive.  
 My best friend died. I need a friend to sit with.  
 My Mom's in Heaven. I can't live alone anymore.  
 Where is Heaven? I need someone for my kids.



# New Challenges and Crises

Death as “double injustice”

Disability enough to deal with, why this?

Aging, disability, death=curses

Anger by staff and others at

- Family (and vice versa)
- Other staff
- Losses



## Challenges and Crises (cont.)

### Pressures and Paradoxes

- ▶ “They don’t understand” vs. “Move on quickly.”
- ▶ Pressure to fill the empty slot, bed, or place at the table
- ▶ Highlights the importance of relationships, not program or plan.
- ▶ “They don’t seem to get over it.”



Currents in DD systems and care are toward growth, development of potential, new life. End of life not in the plans.

- When it happens unexpectedly, it becomes "critical incident report," too often assumed to be someone's fault. Paperwork and investigation compounds grief.
- Currents in health care toward healing, cure, fix, death too often enemy and disability evidence of failure.
- Hospitals too often dangerous places for people with severe disabilities.

## The Perfect Storm



## End of Life and Death often Lonely for Stigmatized People

To counter that:

- Recognize and bring together any current relationships in a community of support
- In age of self determination, help people plan and give them choices
- Build even wider circle as they face death

So, what to do?



Recognize:

Loss and grief will be there, whatever the level of disability.

Losses come in many forms: deaths, end of relationships, staff change, caregiver change, moves, change of valued routines, loss of pets, friends.


Supports need to be inclusive, but also person-centered and family-centered, in their cultural and religious context.

"They" are often better at sharing grief than "we" are.




## Guiding Principles


Reverse the questions. When asking about how to support someone, how would you support anyone else?



None of us completely understands what death means, but we all experience loss.



We all act our grief, usually but not always in family and culturally accepted ways



Non-verbal supports may be more important than verbal. Presence and Participation more critical than cognitive ability.



## Guiding Principles (continued)

Pull in the people who have been supports in the past and present. Support the supporters.

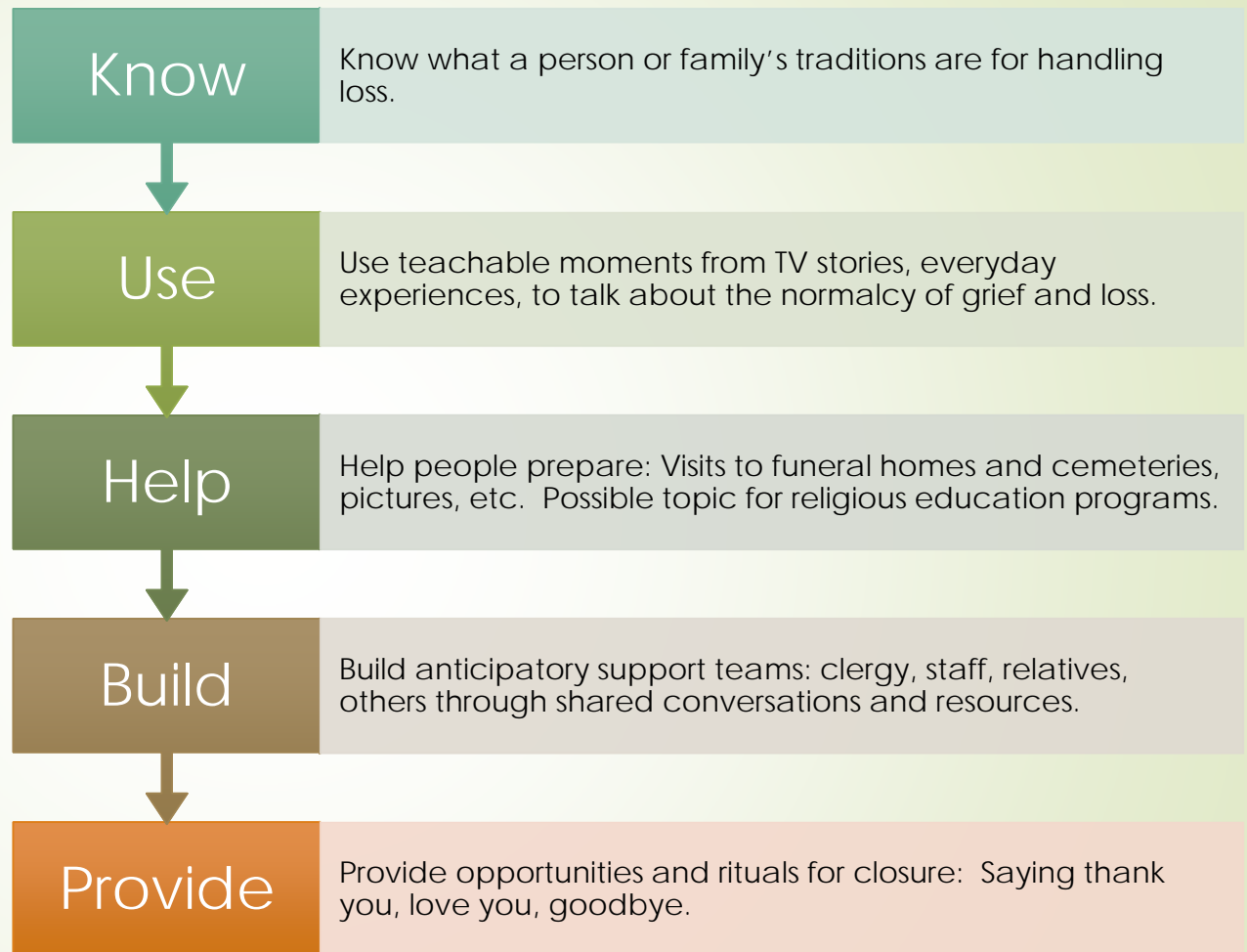
The power is in the community of mourning and support. Your ministry is one of them.

It takes time for everyone.

Think of grief as circles, not straight lines. We live through it, not "get over it."

What we  
can we  
encourage  
others to  
do.

Planning  
ahead



# My Health Passport

If you are a **health care professional** who will be helping me, **PLEASE READ THIS** before you try to help me with my care or treatment.

My full name is: \_\_\_\_\_  
I like to be called: \_\_\_\_\_  
Date of birth: \_\_\_\_ / \_\_\_\_ / \_\_\_\_  
My primary care physician: \_\_\_\_\_  
Physician's phone number: \_\_\_\_\_

Attach your picture here!

This passport has important information so you can better support me when I visit/stay in your hospital or clinic.  
Please keep this with my other notes, and where it may be easily referenced.

Signature: \_\_\_\_\_ Date completed: \_\_\_\_ / \_\_\_\_ / \_\_\_\_  
I can talk to this person about my health: \_\_\_\_\_  
Phone number: \_\_\_\_\_ Relationship: \_\_\_\_\_

**I communicate using:** (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



## Pre-Death Supports

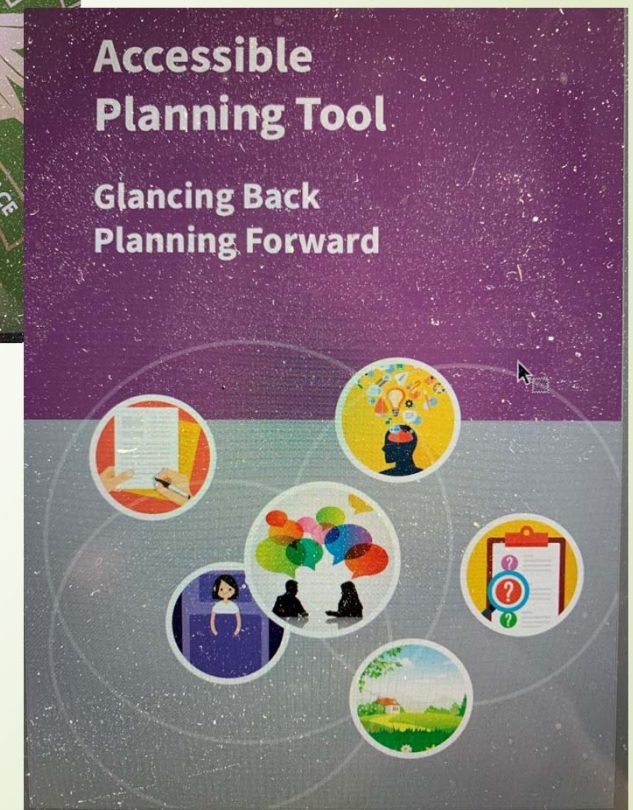
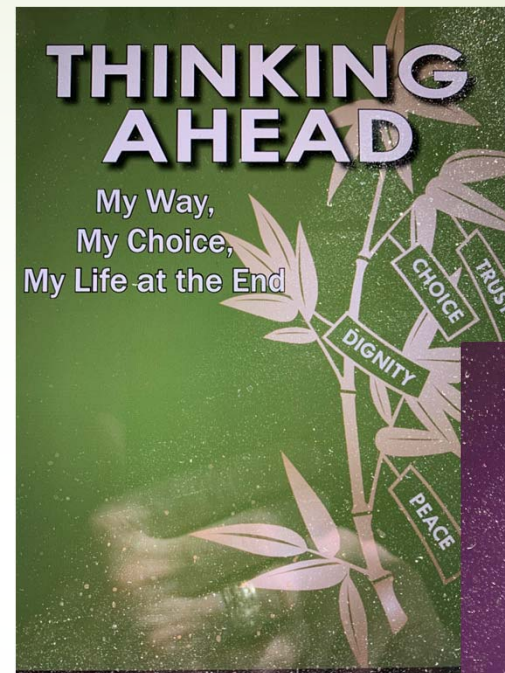
- Individualized Choices. Don't assume someone does not know. Or supported choices with very close friends.
- In illness at home or hospital, make visits possible by staff, friends, anyone who knows the person who wants to come. Helps the person and is a witness to medical staff.
- Help medical staff SEE the person they are caring for.

Health Care Passport is one way to do so.



**Talking End of Life**  
...with people with intellectual disability

*MyGrief.ca*



<http://www.aging-and-disability.org>



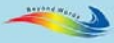


## Ann has Dementia

Sheila Hollins, Noëlle Blackman  
and Ruth Eley  
illustrated by Lisa Kopper



paperback



## When Mum Died

Sheila Hollins and Lester Sireling  
illustrated by Beth Webb



paperback



## When Dad Died

Sheila Hollins and Lester Sireling  
illustrated by Beth Webb



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## Am I Going to Die?

Sheila Hollins and Irene Tuffrey-Wijne  
illustrated by Lisa Kopper



paperback



## When Somebody Dies

Sheila Hollins, Sandra Dowling  
and Noëlle Blackman  
illustrated by Catherine Brighton



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# Key Strategies for Grieving

- ▶ First, recognize it and welcome it. "Grief delayed is grief denied and grief denied is grief delayed."
- ▶ Create a safe place for it. A sanctuary.
- ▶ Be alert for behavioral expressions.
- ▶ Assist in appropriate behavioral expressions, e.g., cards, photos, letters, talking about feelings and memories, sending flowers, taking food, etc.
- ▶ Involve "their" community: friends, housemates, staff, teachers, coaches, others in programs, congregations, work, ex-staff



# Key Strategies for Grieving

- ▶ Accurate and honest information and support to process questions/feelings
- ▶ Enable maximum involvement in the social and spiritual activities surrounding death, including planning.
- ▶ Keep connected with key supportive relationships: Who would you turn to?
- ▶ Maximize opportunities for expression of grief and condolences.
- ▶ Jeffrey Kaufman: *Helping Adults with Mourn*







## Creative Strategies

- Talk with other families, staff, etc. about what they have seen.
- Individualized rituals of loss and celebration in addition to main funeral or ceremony.
- Pre-visits to places where rituals will take place.
- Involve person with IDD in some way in the planning and leadership of services.
- Plan a variety of individualized ways of remembering and memorializing: pictures, photo albums, memory boxes, favorite foods or places, anniversaries, and more

# Planning Earlier for Accompaniment

## Talk

If you are a support agency, talk with individuals and families as soon as they come into your care about experiences and traditions in their family for handling grief and loss.

## Use

Use this as a time to explain what you think is important as an agency.

## Provide

Provide training to your agency staff on grief, loss, and end of life policies and practices.

## Help

Help an older person get more connected as they age. (Church, hobbies, interests)

## Develop

Develop a "Grief Support Team" of agency staff, clergy, counselors, health care staff, funeral home staff from across the community who care and know about end of life experiences for people with IDD.



## Paradoxes of Roles

- Staff, family, and/or friend
- “Be with” as well as “do for”
- “Care for needs” as well as “celebrate gifts.”
- Specialized supports vs. “give it away”
- Know what we don’t know, and use that to invite others in.



## Resources (Selected)

For a more extensive list, see resource listing accompanying the powerpoint.

- ▶ **Helping People with Developmental Disabilities Mourn: Practical Rituals for Caregivers.** Marc Markell, Ph.D. Fort Collins, CO: Companion Press.
- ▶ **Lessons in Grief and Death: Supporting People with Developmental Disabilities in the Healing Process.** By Linda Van Dyke,
- ▶ **When Somebody Dies.** S.Hollins, S. Dowling, & N. Blackman. Other titles in the Books Beyond Words series <https://booksbeyondwords.co.uk> include **When Mum Died, When Dad Died, Am I Going to Die?**, and **Ann has Dementia.** Adult picture books to use in conversations with non-readers.
- ▶ **Website for one of the authors of a number of the Books Beyond Words:** <http://www.tuffrey-wijne.com>
- ▶ **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.  
<https://www.caresearch.com.au/tel/tabid/4881/Default.aspx>



## Getting more specific: Autism

Autism is a neurological disorder characterized by deficits in both language and communication.







## Autism & Grief Project

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# Autism & Grief

Supporting autistic adults in grief and loss

GRIEF IS A SPECTRUM TOO  
Stories About Grief and Autism

**Autistic adults describe their experiences of grief and loss in this compelling six-minute video by Exceptional Minds, a Hollywood studio that trains and employs animation artists on the autism spectrum.**



DSM-5:  
Autism  
Spectrum  
Disorder

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Persistent deficits in social communication and social interaction

---

Restricted, repetitive patterns of behavior, interests, or activities

---

Symptoms are present in early childhood

---

Symptoms limit or impair everyday functioning or relationships

---

(Tierney, 2015)



## Common Behaviors in ASD

---

Decreased eye contact

---

Uneven development of skills

---

Resistance to changes in routine

---

Marked hyperactivity and/or extreme passivity, which may alternate

---

Less demonstration of typical signs of affection

---

Odd body movements or postures (flapping, spinning, etc.)

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(Challman, 2015)



## So what might that look like?

- ▶ Looking down, instead of at you when you speak
- ▶ Not answering questions, or not answering right away
- ▶ Not wanting to be touched
- ▶ Repetitive rocking, swaying or bouncing
- ▶ Walking only on toes
- ▶ Flapping hands
- ▶ Making noises that are not words



## Universal Dimensions of Grief

Very individualized...highlighting importance of knowing and adapting strategies to each autistic individual

No universal stages of grief

Rollercoaster, not a timeline.

Multiple kinds of losses, e.g., loss of support staff, routine, home, pet, etc. Social circle may be more limited

Physical and cognitive symptoms, as well as emotional and spiritual



## For People with Autism

There may be no outward change in behavior, which does not mean lack of understanding or sadness. Assume competence.

Too often assumed that they will not understand, or should be protected from loss... "disenfranchised grief," , grief that is not recognized or respected.

Can cause regression, anxiety, and stress... disconnect from feelings.

Sometimes increase in behaviors used to soothe sensory overload

Uncertainty about social and cultural rituals related to grief and mourning



## Strategies


Be	Be clear, explicit and deliberate with your words. No euphemisms, e.g., "passed away," "sleeping," etc.
Repeat	Repeat as needed. No blame for this happening
Be	Be clear about what will happen next and offer choices about how to proceed in sharing news and coping with loss. (e.g. Books Beyond Words)
Provide	Provide reassurance and openness about your own feelings, i.e., model.
Address	Address sensory challenges, e.g., visit to hospital, funeral home, etc. Provide companion who is trusted and known.

# The Importance of Ritual



- ▶ Remember the importance of rituals, social, cultural, religious, and personal.
- ▶ Rituals and customs are expectations and traditions that have developed over time as ways of living out, and “acting out” our grief.
- ▶ As possible, help an autistic person learn about those rituals as they come up in daily living, what happens, etc.
- ▶ Give choices in what to attend while also educating others about the importance of their doing so. EG, help clergy or funeral directors know what to expect in terms of a person’s typical behavior and reassure them it is all right.
- ▶ Help in development of personal rituals of remembrance.





## In other words:



Educate and explain



Communicate about typical behaviors, in “both” directions.



Model and demonstrate responses and interactions



Choices about what they want to do, ways they want to participate and options for comfort or leaving if needed.



Provide choice about who they would like to accompany and support them.



Reflecting and processing afterwards...at their speed.



# Other Online Resources

- <https://www.autismspeaks.org/family-services/resource-library/bereavement-and-grief-resources>
- <http://www.autismsocietyppgh.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-needs-about-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>

# Disability and Spirituality

RECOVERING WHOLENESS

William C. Gaventa



► 2023 Resource List re: End of Life, Grief, and Loss. Email:

[Bill.Gaventa@gmail.com](mailto:Bill.Gaventa@gmail.com)

► One chapter in the book expands the ideas in this webinar on Aging and End of Life issues. (Baylor University Press)

► Feedback on the Autism and Grief website welcome, and stories.

► Thank You!