INTELLECTUAL & DEVELOPMENTAL DISABILITIES
PALLIATIVE CARE NETWORK

MODULE E: LOSS, GRIEF and BEREAVEMENT GUIDANCE

Supporting people with IDD; Supporting Family;

Supporting Staff

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LOSS, GRIEF AND BEREAVEMENT GUIDANCE

Grief and bereavement are universal experiences that occur following the death of a cherished person. These experiences may also occur following any significant loss (e.g., divorce, unemployment). PWIDD experience multiple losses throughout the course of their lives, along the illness journey, due to death or other events. Historically, these losses may have been ignored due to the mistaken assumption that PWIDD do not experience grief. In this section, we will review supporting PWIDD through the grief process, supporting staff, and supporting family. [1,2,3]

Ethical Reminder: Supporting a grieving person with IDD, family, and other member(s) of the *Circle of Support* requires being present and showing empathy and compassion.

Assuming PWIDD do not want to / cannot participate in discussions and events related to dying and death is neglectful.

SUPPORTING PWIDD

KNOWLEDGE POINTS:

Caregivers and professionals have often excluded people living with intellectual disabilities from talking about death or being involved in death-related rituals, such as funerals, out of an intention to "protect" them.[4] In fact, research shows that PWIDD want to talk about death, dying, and bereavement and that concrete experiences (e.g., attending viewings, funerals, visiting the cemetery) can help people with intellectual disabilities better understand the concept of death. [5,6] End of life rituals (e.g., funeral, memorial, burial) are important across cultures and religions. People living with intellectual disabilities should be offered the opportunity to attend these events if they choose. Depending on their life experiences and relationship with the deceased, they may need some support and preparation to attend and participate in the ritual in a meaningful way.

Ethics Pearl: People experience various losses throughout their lives and illness journeys. Grief and bereavement are universal experiences which would benefit from a "people-centred approach".

Screening and Assessment – Determining Who May Benefit from Additional Support

PWIDD experience loss and bereavement much like anyone else does, however, there may be some circumstances when there is concern for how a person is grieving (or not grieving as 'expected'). People living with intellectual disabilities often have layers of significant loss in their lives, which may have gone unrecognized and unresolved, and are at risk of experiencing grief that is complicated due to several factors:

- significant loss histories
- marginalized identities

- grief that is disenfranchised (not socially recognized as grievers, their losses are not deemed significant)
- significant secondary losses following a death (e.g., residence, possessions, relationships, community)

This is distinguished from complicated grief, now the diagnostic label Persistent Complex Bereavement Disorder (DSM-5-TR)[7], for which valid and reliable screening tools are currently under development and investigation[8,9].

Indicators that someone is experiencing grief occur across multiple domains, including, emotional, physical, cognitive, behavioural, social, and spiritual. Figure 1. outlines common grief reactions. Staying connected and updating the person's primary health care provider is a good practice (to be aware of family illness history, avoid diagnostic overshadowing, provide context to the person's situation). If the person expresses or is observed to have experiences in the "When to be Concerned" column, they should seek further guidance from their primary care provider (i.e., family doctor or nurse practitioner).

It should be noted that people in the severe or profound range of intellectual disability may have difficulty expressing their grief in words.[10] They may be distressed by the change in routine or expect that their loved one will return. They may express their grief through their behaviour.

Ethical Reminder: Don't forget to consider the grief needs of other people with IDD in the home who are dealing with the illness and eventual loss of their friend/housemate who has a serious illness.

Some people living with intellectual disabilities may also have a diagnosis of autism. People may assume that autistic individuals do not experience emotions connected to grief and loss. This is not true! Autistic people do have emotions and they grieve. They may struggle to articulate, process, and regulate their emotions and can have difficulty reading social cues, especially when under additional stress. In addition, how they appear to others may not convey their internal emotional state.

ACTION POINTS: "GOOD" PRACTICE STANDARD

- **Strategies to help when informing a person with IDD that someone close to them has died [11, 12,13]**
  - Choose a quiet and private setting with few distractions.
  - If possible, have someone the person trusts and knows well deliver the news.
  - If possible, choose a setting that is familiar and comfortable to the person.
  - Keep in mind the person's sensory needs: what tactile/visual (colours, lighting), sounds are comforting or distressing to the person?
  - Consider how the person communicates receptively and expressively. Do they use pictures, a communication device, or express themselves verbally or in writing?
  - Consider what the person already knows about the situation. Was the death sudden (e.g., car accident) or after a lengthy illness? This can impact how the person understands the information.
  - Start the conversation by indicating that you want to talk about the person who died. You can then say you have some sad news to share.

Figure 1.

The Grief Journey

Adapted for IDD specificity [14, 15]

*Domain**	When a Death Occurs	Adjusting to the Loss	As Life Continues	When to be Concerned**
Emotional	Crying, sobbing, wailing, anger, blame, guilt, numbness, indifference, emptiness, loneliness, helplessness, anxious, fear, overwhelmed, irritable, relief, sadness.	Ongoing emotional reactions – may be intense and/or conflicting. Magnified fear for self and/or others.	Intensity of emotions ebbs. Feels less numb. More at peace, less guilt/blame. Able to regulate emotional 'waves'.	When sadness has evolved into suspected depression (seek medical opinion). Strong emotions of self-blame, guilt persist. Difficulty regulating emotional state persists. Increased levels of anxiety that interfere with daily activities.
Physical	Digestive upset, shaky, shortness of breath, heart palpitations, restlessness, hyperactivity, low energy, weakness, aches and pains, sleep disturbances, appetite changes, sense of emptiness.	Ongoing physical reactions can include tiredness, restlessness, changes in sleep and appetite, digestive upset.	Physical symptoms brought on by the loss subside. Sleep and appetite patterns have settled. Deep sense of emptiness lightens.	Sleep/eating continues to be disturbed. Continue to lack energy and not return to usual physical activities. Continue to have physical symptoms related to palpitations, shortness of breath, and unexplained pain.
Cognitive	Confusion, forgetfulness, poor concentration, daydreaming, can't stop thinking about person and their death, "I'm going crazy", nightmares, dreams.	Have questions about what happened, memory problems, vivid dreams/nightmares, difficulty concentrating and/or understanding. May perseverate both cognitively and behaviourally.	Concentration and memory have improved. Can remember person/events with less difficulty. Better understanding of the death (and related losses). Dreams and nightmares less disturbing.	Suicidal thoughts/actions. Perseverating thoughts and behaviours continue without relief. Continue to be distressed by unanswered questions.
Behavioural	Avoiding people/activities, seeking comfort, emotional outbursts, destruction of property, hitting head/harming self, change in ability to communicate.	May seek out person who died. Perseverative behaviours (e.g., ongoing movement, asking where person is repetitively). Isolating self from others.	Returns to enjoyable activities. Able to manage emotions, thoughts, and physical reactions through coping such as walking, communicating upset, etc.	Self-harm and harm of others and/or destruction of objects continues. Continues to isolate self from others. Misusing substances (e.g., alcohol, street drugs/ prescription medications, marijuana).
Social	Avoiding people/activities, seeking comfort, unrealistic expectations about self and/or others, want to attend rituals (i.e., funeral, burial), want to avoid rituals.	Finding ways to stay connected to the person who died (i.e., talking to them, looking at photos, having mementos). May want company/support but unable to ask. Self-consciousness. Rushing into new relationships.	Has found a comfortable ongoing connection with the deceased (if wants to maintain this). More interest in daily affairs of self/others. Ability to be with/reach out to others. More energy for social visits/events.	Ongoing isolation from previously enjoyed activities (e.g., work, friends, outings). Overly social, avoiding addressing the loss.
Spiritual	Blaming God, question meaning, hopelessness, wanting to die or join the person who died, dreams, extraordinary experiences (i.e., seeing person's 'ghost').	May question their faith and/or seek out faith connections. Trying to contact the person who died (e.g., talking out loud to them). Sensing the presence of the person who died. Continued search for meaning.	Reconnection with meaningful religious/spiritual beliefs. Sense of new meaning or purpose. Recognition of death as part of life cycle. Integrating the death into one's own personal narrative.	Ongoing sense of hopelessness and wish to die to be with the deceased. Extraordinary experiences, lack of religious/spiritual connection that is disturbing to the person.

*Don't assume that a person is not grieving because none or only a few of these indicators are present. Everyone has unique grief reactions, and the impact of loss needs to be considered, regardless of reactions present or absent.
**Any grief reactions that continue to interfere with the person's daily activities over a period of time are important indicators to seek further support/intervention.

- Provide information about the death in clear language and avoid getting lost in detail (e.g., they died in hospital, they died in their sleep, they were not alone, etc.).
- Use concrete language (person died) and avoid metaphors or euphemisms (e.g., went to sleep, passed away) for death. In situations where it is considered culturally insensitive to use the words death or died, it may help to review what death is. Depending on the person's knowledge of death, explain what death is, possibly using visuals (e.g., the person stopped thinking and feeling, heart stopped beating, etc.).
- Label the emotions the person may be experiencing to both validate them and give them some language to describe their experience.
- Take your cues from the person.
  - If they have questions, answer them to the best of your ability.
  - If they are quiet, be present and offer comfort and assistance.
- Ask the person what would be helpful in the moment (e.g., time alone, contact someone close to them, calming activity, soothing drink, fresh air).
- If the person is questioning or confused, repeat the information as needed. Keep in mind that some people need concrete evidence of the death (e.g., see the body, attend a memorial) to fully process it.

▶ **Strategies to help when preparing people to participate in end-of-life rituals:**

- Having a friend, family member or staff member attend with the person to offer support if needed.
- Obtain information on any spiritual/cultural practices that the person may need to observe and/or participate in during the end-of-life rituals.
- Provide the person with information on what will take place. Use visuals or a plain language tip sheet (please see tools and links) as needed.
- Practice with the person what they may need to say or do at the end-of-life ritual. For example, offer condolences or share a memory in front of those gathered.
- Acknowledge that while it may be an emotional experience, it can help others know they are not alone in their grief.
- If the person does not want to attend end-of-life rituals, respect their choice.

GRIEF and BEREAVEMENT SUPPORT

▶ Most people can move through their grief experience with support from their existing connections.

▶ Check in with the person to see how they are doing.

▶ Offer to connect them with community grief supports (e.g., support group, peer support, religious leader, Elder) following the death, even if the person does not want to talk about their grief.

Individual counselling with a registered mental health professional (e.g., social worker, psychologist, psychotherapist) may be needed if:

- the person has limited social support.
- the death was particularly traumatic for the person.
- the death has brought up issues from the past.
- the person has experienced multiple losses in a short span of time.
- the person has pre-existing mental health diagnoses that are exacerbated by the loss (e.g. depression).
- the person requests it.

- ***Special considerations for people within the severe or profound range of ability*** [10,16]
    - Concretely explain that the person died (e.g., using photos and objects) as often as needed.
    - Offer the individual opportunities to participate in any memorial activities as they are able.
    - Sensory-based strategies may be useful if the person communicates non-verbally (e.g., photos, objects, smells, sounds).
    - Retain as many routines as possible to create a sense of security.
    - Offer comfort and support (e.g., pillow made of loved one's clothing).

- ***Special considerations for Autistic people with an intellectual disability:***
    - Check in with the person and ask how they are doing. You may need to ask specific questions regarding various life domains (e.g., eating, sleeping, mood, missing the person who died) and their regular routines.
    - Explain common grief experiences and that people also have variations in their grief.
    - Review and explain any memorial activities that may be taking place and ask the person if they would like to participate, and how. Do they want to be a part of a group or more at a distance? Do they want someone to accompany them? Is there anything they are worried about happening?
    - The individual may return to, or increase, engagement in personally comforting routines (e.g., repeatedly watching certain videos, stimming) as a way to cope.
    - Visuals and social stories may help the individual process the experience.

RESOURCE LINKS and TOOLS

- Let's Talk About Death, Down's Syndrome Scotland.
- Resources | PAMIS
- Autism & Grief - Autism & Grief Project
- Home | Bereaved Families of Ontario
- Feeling Sad When Someone Dies - Steffi Portal Canada
- Books Beyond Words – a series of illustrated books (available in print or on-line versions) explaining death and illness to people with intellectual disabilities.
- Supporting People with Disabilities Coping with Grief and Loss - an Easy-to-Read Booklet available for purchase.
- Aging and Disability | Grieving - L'Arche Canada
- Supporting someone with intellectual disabilities: eLearning Module - Canadian Virtual Hospice
- Talking End of Life (TEL) with people with intellectual disability
- Loss, Grief, and Mourning Resources - PCPLD Network
- Making a Difference Toolkit, Keele University (2014)
- End-of-Life-Care-Route-to-Success-learning-disabilities.pdf
- delivering-end-of-life-care-for-people-with-learning-disability.pdf

SUPPORTING STAFF

KNOWLEDGE POINTS [2, 17]:

- Staff working with people with intellectual disabilities, especially in a residential setting, form close bonds with the individuals they support.
- Staff can expect to experience a range of emotions while providing palliative care and following the death of a client.
- It is essential to acknowledge and validate staff grief experiences.
- Debriefing provides staff with an opportunity to acknowledge their grief and loss in their own way.
- Debriefing can occur shortly after a client death or as part of regular team meetings.
- Staff benefits include:
    - Opportunities for social support and to share coping skills.
    - Reduced feelings of isolation.
    - Normalizing emotional reactions to difficult situations.
    - Opportunities to discover and find meaning in the experience.

Ethics Pearl: Good Organizational Ethics requires supporting staff, especially during times of loss, grief, and bereavement.

ACTION: "GOOD" PRACTICE STANDARD

- Discuss grief and bereavement at employee on-boarding and staff meetings to raise awareness and promote discussion.
- Provide staff opportunities to share and process their grief experience after the death of a client (e.g., official memorials or unofficial rituals for staff).
- Make information on EAP (Employee Assistance Provider) and community bereavement supports readily available for employees who may not want to share in a group setting or who would benefit from more personalized support.
- Utilize peer-led debriefing strategies. (See Tools & Links)

RESOURCE LINKS and TOOLS

- Grief and Bereavement Supports for Health Care Workers – Hospice Palliative Care Ontario (HPCO)
- Peer-led debriefing models to help guide and structure the conversation:
    - Peer Led Debriefing Toolkit – Quality Palliative Care in Long Term Care Alliance
    - Schwartz Rounds – The Schwartz Center
    - Well-Being Debriefings for Health Care Workers - Facilitator Manual, CAPC (2025)
    - Low Impact Debriefing – The TEND Toolkit

SUPPORTING FAMILY (IMMEDIATE AND EXTENDED)

Every family's experience of loss and grief is unique. That said, the role of family members to someone with an intellectual disability can add to the complexity of the grieving process.

Ethical Reminder:
Grief may occur over a continuum, which can encompass diagnosis of a life-limiting illness through bereavement. Providing grief resources/supports earlier in this continuum supports continuity of bereavement care.

Do you know who provides grief and bereavement support in your area?

Who supports grief and bereavement for PWIDD?

KNOWLEDGE POINTS:

- Grief can be a common emotion that is navigated multiple times by immediate family members of a person with an intellectual disability over the course of their relationship.[18]
- If the person had a history of significant medical issues requiring hospitalization, parents and siblings may already have experienced some degree of anticipatory grief whenever these events have occurred.[19]
- In some families, the intellectual disability may have affected the emotional attachment of family members. This could result in issues of guilt, anger, and regret which may potentially complicate the grief of those surviving family members.[19]
- It is not uncommon for family members to experience disenfranchised grief and, amongst siblings, survivor's guilt. The latter can surface unexpectedly when the person with an intellectual disability dies, especially if their death was unexpected.[18]
- When a person has been ill and/or in pain for a prolonged period and death has come as a respite, feelings of relief in family members can be accompanied by feelings of guilt.[18]
- The death of one's child, regardless of their age, is the most distressing and poignant event in the life of a parent.[20] Paradoxically, in stark contrast to parents of neurotypical, healthy children, it is not uncommon for parents to hope that they outlive their son or daughter with an intellectual disability.[21]
- For parents and other family members who have been long-term primary caregivers, a way of life and an identity can vanish suddenly when their family member with an intellectual disability dies. This can contribute to a loss of their sense of purpose.[18, 22]
- Family members may not have shared much about their loved one within their *Circle of Support* due to the stigma connected to intellectual disabilities.
- Family members may feel more comfortable with intellectual disability community members because they "get it."

ACTION: "GOOD" PRACTICE STANDARD

- Acknowledgement of the death of their loved one, along with the associated loss and grief, is important.[20]
- Be mindful that the family's involvement with developmental services, unless they have another child with an intellectual disability, will likely come to a rather abrupt end. This lack of continuity can create a challenge for the family in trying to 'move on.'[20] Some families would benefit from a supportive check-in from a member of the care team and an offer of further resources (e.g., bereavement support services).[20]
- Some families may benefit from assistance to connect with support services.[22]

RESOURCE LINKS and TOOLS

- Palliative Care for the Patient with Incurable Cancer or Advanced Disease Part 3: Grief and Bereavement, BCGuidelines.ca (2017)
- Regional Affiliates, Bereaved Families of Ontario
- Bereaved Families of Toronto

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