Grief & Bereavement Literacy Series

Session 29: **"*Honouring Grief in Long-Term Care Communities: Struggles and Strategies*"**

Presenters:

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Agenda Item	Discussion
Introduction & Objectives	**Overview** • The session provided an evidence-informed overview of why grief is a significant and under-recognized issue in long-term care settings. • It was noted that long-term care is often the last place residents die, with approximately one in four Canadian long-term care residents dying in the home each year. • The presenters highlighted that the median survival after admission to long-term care in Canada is approximately 18 months, allowing time for deep relationships to form among residents, families, and staff; making grief more personal and complex. It also pointed out that long-term care homes are more resource-constrained than settings like hospice, and BC lacks a standardized, mandated process for grief and bereavement support. • It was further noted that the Long-Term Care Quality Framework Policy Directive does not currently include grief and bereavement indicators, limiting systemic accountability. **Objectives** The session aimed to: • Describe the struggles with grief experienced by residents, families, and staff in long-term care: recognize the types of grief present • Identify strategies that support healthy grieving in LTC communities. • Understand how and where to access BC-based grief and bereavement resources.
Presentation Key points	**Key Learnings** **Defining Grief, Bereavement, and Mourning** The presenters provided foundational definitions to frame the session's discussion of grief. • Grief was defined as the range of emotions experienced following the loss of someone or something cherished. It was emphasized that grief is neither good nor bad—it simply exists. • Bereavement was distinguished as the period of experiencing a loss, while mourning was described as the outward expression of grief. • The presenters noted that, rather than grief diminishing over time, people grow around their grief. Mourning plays an important role in helping individuals adapt and function following a loss. **Conclusion** • Grief, bereavement, and mourning are distinct but interconnected concepts that are foundational to understanding the long-term care experience. **Types of Grief in Long-Term Care** The presenters described multiple forms of grief observed in long-term care settings, drawing on research and lived experience. • **Visible and Invisible Grief:** Distinguished between visible grief (death-related and socially recognized) and invisible grief (non-death-related and often overlooked), such as the loss of privacy, independence, or lifestyle.

- **Disenfranchised Grief:** Described grief that is not openly acknowledged, publicly mourned, or socially supported. Many losses in long-term care, such as a resident moving rooms following the death of a spouse, can become disenfranchised.
- **Anticipatory Grief:** Explained as the emotional suffering experienced before an anticipated loss. This commonly occurs during admission to long-term care or as cognitive decline progresses. Families often struggle with balancing hope while preparing for loss, while staff may experience anticipatory grief when residents' needs can no longer be met within the care setting.
- **Ambiguous Loss:** Described as grieving a loss without a clear ending or resolution, such as when a loved one with dementia is physically present but has undergone significant cognitive changes, resulting in altered relationships and family roles.
- **Disorientation and Disenchantment Grief:** Occurs when expectations of long-term care differ from reality, such as expecting constant care despite staffing limitations or expecting recovery when care is primarily palliative.
- **Cumulative Grief:** Refers to the ongoing experience of repeated losses among residents, families, and staff—including non-clinical staff such as housekeeping and maintenance personnel—highlighting that grief in long-term care is rarely associated with a single event.
- **Complicated (Prolonged) Grief:** Characterized by persistent, intense grief that significantly interferes with daily functioning over an extended period.
- **Masked Grief:** Occurs when grief is consciously or unconsciously hidden. Individuals may express grief through anger, withdrawal, or physical symptoms without recognizing grief as the underlying cause.

Conclusion

- Long-term care settings involve multiple, overlapping types of grief that affect all members of the Long-Term Care Village.
- Many of these grief types are invisible or unacknowledged, making intentional recognition and support essential.

<u>Grief and Trauma in Long-Term Care</u>

The presenters explored the interconnection between grief and trauma, emphasizing the importance of trauma-informed care.

- Trauma is common among older adults in long-term care, particularly those with previous experiences of war, abuse, or repeated life trauma.
- Past trauma may be triggered by illness, functional decline, loss of independence, the death of loved ones, or the transition into long-term care.
- Trauma may present differently across groups:
    - **Residents:** Withdrawal, agitation, refusal of care, or distress during personal care.
    - **Families:** Distrust of the care team, increased requests for updates, or difficulty accepting a prognosis.
    - **Staff:** Burnout, emotional exhaustion, moral distress, and reduced empathy.
- Repeated losses can reactivate previous trauma, while unresolved trauma can intensify grief responses.
- The presenters encouraged shifting from asking, *"What's wrong with this person?"* to *"What might this person have experienced?"* as a guiding principle for compassionate, trauma-informed care.

Conclusion

- Grief and trauma are deeply interconnected in long-term care; a trauma-informed approach is essential to reduce distress and create safer, more supportive care environments.

<u>Struggles and Strategies Across the Care Journey</u>

The presenters outlined the grief struggles residents face and practical strategies to address them.

Resident Struggles

- Residents may experience fear of the unknown during the transition into long-term care, along with the loss of familiar routines, independence, privacy, community, cultural food preferences, and personal identity.
- Many residents experience loneliness despite living in a communal environment.
- Progressive physical, cognitive, and emotional decline can contribute to a profound sense of loss.

- Some residents fear dying alone or unnoticed, while those with cognitive impairment may be unable to express or communicate their grief.

Resident Support Strategies

- Ease the transition into long-term care by staging admission paperwork, limiting introductions to essential staff on the first day, and gradually introducing additional team members during the first week.
- Implement a **Moving Huddle**, where the interdisciplinary team gathers psychosocial information from residents and families before admission to better understand individual preferences, life history, and support needs.
- Adopt a relationship-centred approach to care by recognizing that *how* care is delivered is just as important as *what* care is provided. Every staff member, regardless of role, contributes to the resident's experience.
- Encourage participation in resident councils to foster belonging, purpose, peer support, and resident engagement in decision-making.
- Apply trauma-informed care by promoting flexibility, choice, environmental modifications, and a strengths-based approach that focuses on residents' abilities rather than their limitations.
- Incorporate reminiscence therapy and opportunities for residents to share their life stories and achievements, helping them maintain identity, purpose, and connection.
- During the end-of-life phase, ensure residents do not die alone whenever possible. Use visual cues to discreetly notify staff of palliative care needs and acknowledge residents who have died through respectful memorial practices within the community.
- Following a resident's death, notify the long-term care community in a respectful and culturally sensitive manner, such as through memorial boards or resident council announcements.

Conclusion

- Grief support for residents must span the entire care journey- from admission through death and bereavement.
- Relational, trauma-informed, and community-based approaches are most effective.
- The Moving Huddle at Minoru Residence is a concrete, replicable example of front-loading support during the difficult transition into long-term care.

<u>Family Grief: Struggles and Strategies</u>

The presenters discussed the unique grief experienced by family members and shared strategies to support them throughout their loved one's long-term care journey.

Family Challenges

- Families often experience guilt, self-blame, uncertainty, and a loss of control when transitioning a loved one into long-term care.
- Many struggle with the loss of their caregiving role while simultaneously feeling relief that their loved one is receiving care.
- Families may feel excluded from care discussions or decision-making, contributing to frustration and distress.
- Caring for someone with dementia is associated with increased emotional burden due to prolonged anticipatory grief and reduced communication with the loved one.
- Families who feel emotionally unprepared for death are at greater risk of experiencing depression and anxiety following bereavement.

Family Support Strategies

- Involve families in the **Moving Huddle** to build trust, establish expectations, and strengthen partnerships from the beginning of the care journey.
- Take time to understand each family's unique circumstances, recognizing the difference between a *difficult family member* and a *difficult family relationship*.
- Offer caregiver supports and self-care resources early, including peer support groups, educational programs, and community organizations.
- Encourage participation in family councils, which provide peer support, shared learning, advocacy, and opportunities to improve the quality of care.
- Prepare families for end-of-life changes by providing educational resources and ongoing communication.

- Following a resident's death, offer meaningful bereavement supports such as dignity walks, memorial boards, room blessings, and dedicated spaces where families can gather and grieve.

Conclusion

- Family grief is complex and spans the entire care journey; proactive communication, community support structures, and culturally responsive practices are essential.
- Family councils are a powerful vehicle for peer support, empowerment, and quality improvement.

<u>Staff Grief: Challenges and Strategies</u>

The presenters outlined the unique grief challenges faced by long-term care staff and organizational strategies to support them.

Challenges

- The emotional impact of working with loss and death is often overlooked in staff orientation and training, representing a systemic gap.
- Staff frequently experience pressure to admit new residents shortly after a resident's death, which can be distressing for the deceased resident's family and demoralizing for staff.
- Staff often struggle to balance developing meaningful relationships with residents while maintaining professional boundaries to sustain their emotional well-being and capacity to provide care.
- Staff may feel compelled to suppress their grief to appear capable to managers and colleagues, while simultaneously expressing compassion to residents and families. This conflicting expectation can be emotionally exhausting.
- Unacknowledged or suppressed grief can contribute to emotional distancing, compassion fatigue, burnout, absenteeism, increased staff turnover, low morale, and reduced quality of care.

Staff Support Strategies

- Normalize conversations about grief and build staff confidence in discussing grief openly. Recognizing and naming emotions is an important first step toward acknowledging grief.
- Foster a psychologically safe workplace through education, supportive leadership, and relationship-centred practices among staff.
- Encourage leadership to facilitate discussions about balancing professional boundaries with compassionate, relationship-based care, helping staff develop a professional identity grounded in whole-person care.
- Promote resources such as *Recipe for Empathy* by Deborah Bakhti, which encourages a shift from transactional to relationship-centred care.
- Develop clear organizational policies, protocols, and handbooks outlining how to support residents and families before, during, and after a death, ensuring all staff understand available processes and supports.
- Encourage participation in the **Palliative Essentials in Long-Term Care** course (available through LearningHub) for nursing and allied health professionals, with a version in development for health care aides.
- Promote the **BC Care Providers Grief and Loss Resource Sheet** as a practical resource for staff supporting residents and families through grief and bereavement.
- Ensure formal supports are available to staff, including debriefing sessions, peer support, supervisory support, the Employee and Family Assistance Program (EFAP), and spiritual health practitioners.
- Integrate trauma-informed approaches into workplace practices by supporting appropriate staffing levels, equitable benefits, peer support, and ongoing education.
- Incorporate meaningful rituals, such as monthly memorial services, memorial boards, condolence cards, and staff notifications of resident deaths, to acknowledge loss and promote healing. The presenters highlighted these practices at Minoru Residence, where approximately 70–80 residents die annually in its 250-bed facility.
- Encourage self-care as an essential component of staff resilience and long-term sustainability.

Conclusion

	• Grief is an occupational reality in long-term care; grief support must become an organizational practice, not just an individual responsibility. • Rituals, relational culture, formal support structures, and trauma-informed approaches are key to sustaining staff well-being and quality of care. **<u>Research Evidence Supporting Grief Care Investment</u>** The presenters summarized research findings demonstrating the positive outcomes of investing in grief care. • Research on art therapy for residents found improvements in communication, social connection, and opportunities to express and process grief. • Studies evaluating staff grief interventions reported stronger team cohesion, greater closure following resident deaths, and reductions in burnout, particularly in the areas of emotional exhaustion and depersonalization. • A family member's reflection illustrated that openly discussing grief helps families process loss throughout the care journey, navigate bereavement more effectively, and make more informed decisions about care. **Conclusion** • Research supports that investing in grief care for the entire Long-Term Care Village produces meaningful, positive outcomes for residents, families, and staff. **<u>Closing Remarks and Call to Action</u>** • Grief is not a problem to be solved but a natural and ongoing part of life that should be acknowledged, normalized, and compassionately supported. • Although grief and bereavement are universal experiences in long-term care, there is currently no standardized approach to supporting residents, families, and staff. • The BC Centre for Palliative Care is actively developing educational resources and quality indicators to strengthen grief and bereavement support within long-term care. • Grief and bereavement support should become a routine, expected, and essential component of quality long-term care policy and practice. **Conclusion** • Grief touches everyone in long-term care; recognizing, supporting, and responding to grief creates more compassionate environments for residents, families, and staff.
Q and A session	**Q&A: Privacy and Confidentiality When Disclosing a Resident's Decline or Death** A question from the audience prompted discussion about how to balance privacy with the need to inform other residents of a peer's passing. **Response:** • One approach shared was to incorporate Goals of Care conversations into routine interactions with residents. During these discussions, residents' preferences are documented, including whether they would like friends or tablemates to be informed if they become seriously ill or pass away. When a resident enters the end-of-life phase, staff review these documented preferences to guide decisions about disclosure. It was acknowledged that unexpected deaths remain particularly challenging to navigate. • Another recommendation was the use of memorial boards as a respectful, non-verbal way to notify residents of a peer's passing. Memorial boards may be discreetly displayed, such as in recessed wall spaces with a light, and can serve as a compassionate way to acknowledge loss within the community. It was emphasized that, in many cases, not informing residents can leave them feeling confused, anxious, or isolated. Thoughtful, permission-based communication is generally more supportive than silence. • It was also noted that some care homes obtain family consent before displaying a resident's photograph or name on a memorial board. In situations involving shared rooms, roommates may be informed that a resident is receiving end-of-life care and that increased family visits are expected, while maintaining the resident's privacy by not disclosing unnecessary clinical details. **Q: Is there a way that palliative care consultants can better support grief awareness and support in LTC?**

	Response: • It was noted that each long-term care home establishes its own organizational priorities and approaches to grief support. Experience has shown that structured staff education, proactive communication with families, and regular staff debriefing are most effective when they become integrated into routine care rather than being treated as separate activities. • It was also explained that palliative care consultants generally do not provide ongoing services within long-term care settings. As a result, grief support should be embedded within long-term care through staff orientation, continuing education, and ongoing organizational support, recognizing that grief is often an invisible aspect of care. • Another perspective highlighted that while palliative care programs may provide grief support to their own patients and families and occasionally offer grief support groups, their capacity is limited and these services are not typically available to the broader long-term care community. This limitation appears to be common across multiple health authorities.
Resources	Resident/Family • 'Taking Care of Me' from the Care for Caregivers • Family Caregivers of British Columbia: Provides province-wide peer support groups, educational webinars, and one-on-one coaching for family caregivers. Visit Family Caregivers BC Support to find programs and resources near Arbutus Ridge. URL: familycaregiversbc.ca • "Now What? Managing the Emotional Journey of Long-Term Care for Families" by Deborah Bakti: An essential book written by a former senior care operations leader and family member. It breaks down the complex feelings of guilt and relief while offering practical advice for connecting with care staff. https://deborahbakti.com/now-what-book/ \ • Vancouver Coastal Association of Family Councils (VCAFC): Help families in their long-term care journey learn about the value of taking part in their loved one's advocacy for quality of life through the family and resident council community within their care home. The Education Portal provides caregiver tips. https://vancouvercoastalfamilycouncils.ca/ • Alzheimer Society of Canada Long-Term Care Guide: Offers a compassionate framework for caregivers moving a loved one into care, helping them balance care recipient needs with their own well-being. https://alzheimer.ca/en/help-information/im-caring-person-living-dementia/long-term-care • As Death Approaches (Vancouver Island Health): overview of common changes Staff • Palliative Essentials in Long-Term Care Course**:** self-paced course designed to help LTC clinicians integrate a palliative approach into everyday care. • **"Recipe for Empathy" By Deborah Bakti:** RECIPE for Empathy lays out six steps to develop new ways of thinking, communicating and connecting with residents and their families by design, not default**. https://deborahbakti.com/book/** • BC Care Providers Grief and Loss Resource Sheet: contains resources that staff working in long-term care homes can refer to in order to support family members through their grief and loss All: Resident, Family, Staff • Canadian Virtual Hospice Grief Resources: modules and resources designed to help understand and move through grief. • BC Bereavement Helpline Grief & Loss Support Brochures – available to order in various languages. Trained volunteers provide emotional support and can refer people to grief and bereavement services near them. • Local hospice societies also play an essential role in supporting people through grief and bereavement. They typically offer a range of services including 1:1 grief support, support groups, and anticipatory grief resources. Find your local hospice society here. • S.U.C.C.E.S.S to access grief support in **languages other than English.** • KUU-US Crisis Line to access grief support **for Indigenous people.** Strategies Interpersonal strategies that honour grief in long-term care • Staging or easing the transition to LTC via respite stays or downsizing. • Preparing expectations and supporting shared decision-making. • Resident peer support, reminiscence therapy. • Trauma-informed care. • Honouring cultural diversity in loss and grief. • Engaging family council as partners in improving grief-aware practices. • Ensuring the person dying is not alone. • Notifying the entire village of LTC about the resident's death. Organizational strategies that honour grief in long-term care • Move-in staff and family huddle.

	• Family council participation - creating outlets for people to process grief through engagement. • Rituals to let others know the resident is transition to bedside end of life care. • Room blessing/memorials to acknowledge grief of entire LTC village. • Organizational processes for grief and nearing death are clear (i.e. handbook). • Make formal grief support available.
Closing, Future Sessions	❖ Video recording ❖ **Past sessions:** • https://www.bc-cpc.ca/echo-project-new-home/echo-project-past-series-and-resources/#1694021429157-e9440b18-3da4 ❖ Action Plan: https://www.bc-cpc.ca/about-us/activities/new-projects/bereavement-study/grief-and-bereavement-support-in-bc-a-collaborative-improvement-action-plan/ ❖ ***Other Links:*** **Joshua's podcast link:** https://www.griefdreams.ca/