

Long-Term Care Community of Practice

Honouring Personhood in Dementia Care



Host & Moderator: Holly Finn, PMP

Guest Speaker: Elisabeth Antifeau, RN, MScN, CHPCN(C), GNC(C)

Date: August 11th, 2022

Territorial Honouring



The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

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The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.



LEAP Long-Term Care

- Interprofessional course that focuses on the essential competencies to provide a palliative care approach.
- Case studies contextualized to the long-term care setting.
- Delivered online or in-person.
- Ideal for any health care professional (e.g., physician, nurse, pharmacist, social worker, etc.) working in long-term care and nursing homes.
- Accredited by CFPC for **27.5 Mainpro+ credits** (online) and **26.5 Mainpro+ credits** (in-person).



Learn more about the course and topics covered by visiting

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Overview of Sessions

Session #	Session Title	Date/ Time
Session 1	Introductory Session	Dec. 9, 2021 from 12-1pm ET
Session 2	The Palliative Approach as Part of the Continuum of Care	Jan. 13, 2022 from 12-1pm ET
Session 3	The Palliative Approach as an Inter-Professional, Team-Based Approach	Feb. 10, 2022 from 12-1pm ET
Session 4	Individuals and their Families as Members of the Team	Mar. 10, 2022 from 12-1pm ET
Session 5	Advance Care Planning	Apr. 14, 2022 from 12:30-1:30pm ET
Session 6	Resources for Long-Term Care	May 12, 2022 from 12:30-1:30pm ET
Session 7	Spiritual and Religious Care as Part of the Holistic Approach	Jun. 9, 2022 from 12-1pm ET
Session 8	Supporting New Team Members	Jul. 14, 2022 from 12-1pm ET
Session 9	Honouring Personhood in Dementia Care	Aug. 11, 2022 from 12-1pm ET
Session 10	Diversity and Inclusion in the Long-Term Care Setting	Sep. 8, 2022 from 12-1pm ET
Session 11	Meaningful Measurement to Support Health System Improvements in LTC	Oct. 13, 2022 from 12-1pm ET
Session 12	Mental Health and Resilience During the COVID Pandemic: Part 1	Nov 10, 2022 from 12-1pm ET
Session 13	Mental Health and Resilience During the COVID Pandemic: Part 2	Dec 8, 2022 from 12-1pm ET

Welcome and Reminders

- Please introduce yourself in the chat!
- Your microphones are muted. There will be time during this session when you can unmute yourself for questions and discussion.
- Use the chat function to ask questions and add comments throughout the session
- Remember not to disclose any Personal Health Information (PHI) during the session
- This session is being recorded and will be emailed to registrants within the next week.
- This 1-credit-per-hour Group Learning program has been certified by the College of Family Physicians of Canada for up to **12 Mainpro+** credits.

Introductions

Host & Moderator

Holly Finn, PMP

National Lead, Palliative Care ECHO Project, Pallium Canada

Technical Support

Gemma Kabeya

Education Research Officer, Pallium Canada

Guest Speaker

Elisabeth Antifeau, RN, MScN, CHPCN(C), GNC(C)

Regional Clinical Nurse Specialist (CNS-C)

IH Regional Palliative Care and End of Life Services

Pallium Canada Master Facilitator & Coach, Scientific Consultant

Disclosure

Relationship with Financial Sponsors:

Pallium Canada

- Not-for-profit
- Funded by Health Canada

Disclosure

This program has received financial support from:

- Health Canada in the form of a contribution program
- Generates funds to support operations and R&D from Pallium Pocketbook sales and course registration Fees

Host/ Presenter:

- Holly Finn: National Lead, Palliative Care ECHO Project, Pallium Canada
- Elisabeth Antifeau: Nothing to disclose

Disclosure

Mitigating Potential Biases:

- The scientific planning committee had complete independent control over the development of course content

Honouring Personhood in Dementia Care

Objectives of this Session

Upon completing the session, participants will be able to:

- Explain what is meant by “personhood”
- Describe the construct of “Self”
- Explain how living with advancing dementia impacts one’s Personhood
- Appreciate how a palliative approach to care can address psychosocial, emotional and spiritual suffering when the person with dementia cannot maintain their Selfhood
- Recognize the role and responsibility of accessing Self through proxy sources to provide person-centred care
- Describe 5 key practice strategies to honour and promote Personhood in Dementia Care



Defining Personhood

What do you think of
when you hear the word
“Personhood”?



Share your thoughts in the Chat...

Personhood Defined

Thomas Kitwood (1988, 1997)

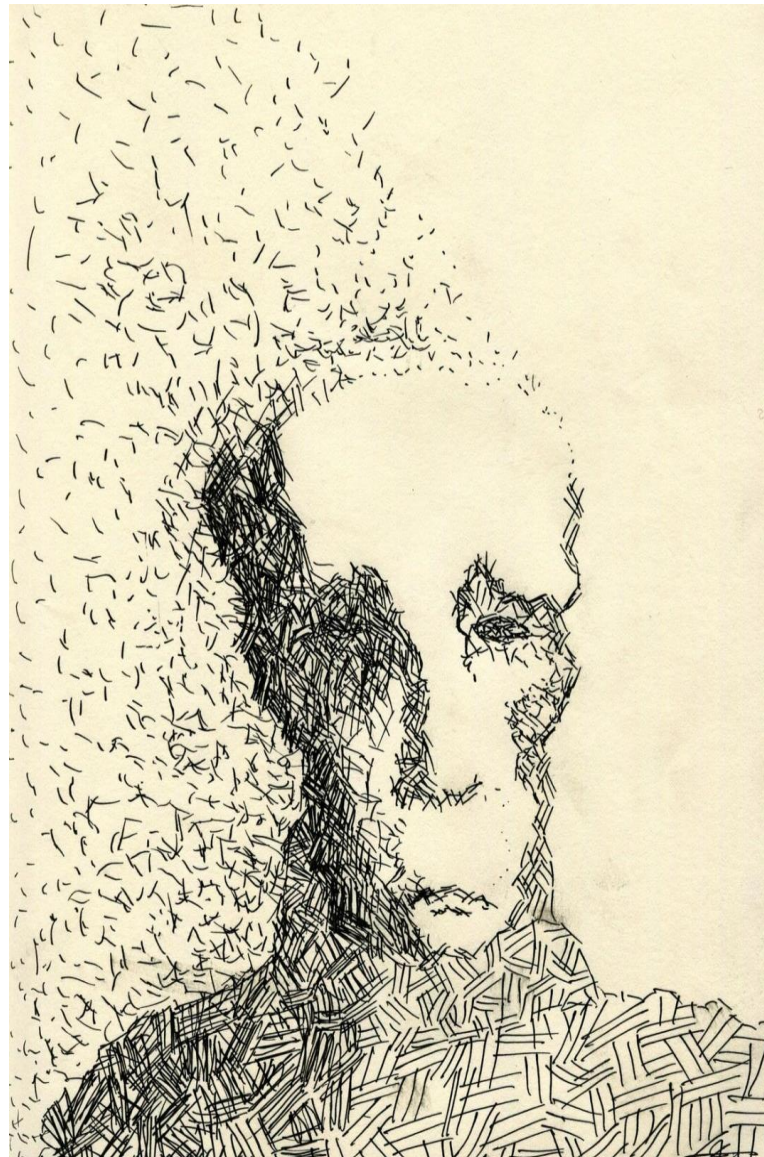
- are the elements of human beings that make them a person
 - is a status that is given by others, assuming *recognition, respect, and trust*
 - an approach to care that brings together communication and relationships
 - 5 core care elements are needed:
 1. Comfort
 2. Attachment
 3. Inclusion
 4. Occupation
 5. Identity
- *“To have an identity is to know who one is, in cognition and in feeling. It means having a sense of continuity with the past; and hence a ‘narrative,’ a story to present to others”(p43).*
 - *Due to declining cognition, persons with dementia need others to “hold their story” and to respond to them as “thou, in the uniqueness of their being”*
(Kitwood, 1997).

Dementia

Is a persistent, progressive brain disease causing cognitive decline over many years+....

So easy to see the many losses and functional declines leading to increasing dependence on others for basic daily care, harder to see retained strengths and abilities

Becomes slowly harder to “see the person that was” before dementia



Often perceived and described as the person is “*fading away*”

But consider...

- Who is this person?
- What is his Life Story?
- How has he navigated the ups and downs of his life?
- Who is he in relation to others? Who loves him? Who knows him?
- What is important to him?
- What does he value? prefer? believe?
- What makes him laugh? Gives him pleasure? joy?

Understanding the construct of “Self”

Our “Self” is an integration of:

- Who we are (and who we are not)
- Our existence in relation to other people
- Delineating self from others & environment
- A sense of self worth
- A sense of meaning and purpose
- A sense of place in the world that continues over time and space
- Self awareness and monitoring and appraisal of personal strengths/ weaknesses, success/failure and control, pleasure

- Personhood recognizes that Self exists and has a unique identity
- Identity is the recognition of the components of Self - in whole and in parts



- D'Cruz, 2021

Linking Personhood and Dementia

- Advancing dementia impacts abilities to access and retrieve emotions, memories, thoughts, adapt behaviours and functional abilities to respond to people and the world around and within the person.
- As dementia progresses, the person increasingly struggles to integrate and maintain the components of Self and Identity.
- Over the dementia trajectory there is also a progressive loss of insight and decisional capacity;
- By mid-stage dementia, there are changes to decisional capacity (e.g., anosognosia) that begin to erode autonomy and independence
- Autonomy and Independence
 - useful to distinguish decisional autonomy from executorial autonomy

(Boumans, 2022)

- A “double death” (Fazio, 2018)
- The need to use a palliative approach in care to ease this psycho-social-emotional symptom burden and improve quality of life



Key Question:

What happens when dementia erodes our sense of Self?



Self *never* goes away...

- Dementia makes it very hard for the person to recognize and maintain Selfhood due to impaired executive functioning (e.g., memories, lost language and interpersonal and environmental cues)
- Self fades but does not go completely away; variable insight into the losses over time can cause distress
- Recent evidence demonstrates that Self persists into end-stage dementia

Norberg, 2019

Persistence and preservation of Self is observable in:

- Synchrony of social interaction with others;
- Recognizing pleasant vs unpleasant stimuli
- 'Flashbulb' memories
- Pronoun use
- Recognizing younger self in photos
- At-homeness vs homelessness
- Communion (e.g., settling with touch, voice and presence from another)



Holding Their Story...

- The fluctuating erosion of personhood in dementia leads to distress and suffering
- Loss of Self is strongly influenced by how other people perceive and treat the person...
- When a person cannot integrate Self, the onus is on HCP to access Self through other sources (proxy)
- Direct inquiry and engagement with the person is a/ways first approach
- Gain insight and appreciation of a lifetime of Self through those who know the person best (family, loved ones, friends):
 - Relationships
 - Life history
 - Beliefs, Values
 - Preferences
 - Habits

Inquiring about the Person

Asking the Person

What do I need to know about you as a person to give you the best care possible?

Asking the Family/Loved Ones*

What do I need to know about your (name of relative or loved one) to give them the best care possible?

Q: When should you use this question where you work?

Using Self information to honour Personhood

How to do this honouring work well?

- Focus less on what is done and more on how it is done.
- Examples of how to honour Self include...
 - Giving choice! (recall, engages decisional autonomy when executional autonomy is no longer possible)
 - Inquiring and respecting known life time patterns, traditions and preferences in daily care
 - Providing meaningful engagement that stimulates, relaxes and provides pleasure every day
 - Learning a bit of history to better understand the context of people's Life Stories

Five Key Care Practice Strategies to Honour and Promote Personhood in Dementia

1. Optimize and Preserve Abilities
2. Support Dignity
3. Honor traditional preferences & habits
4. Foster Quality of Life
5. Lend Voice

- Supporting Personhood is deeply intimate work, using knowledge of the person to guide all aspects of caregiving and conversation
- Use the 5 core care elements of Kitwood's definition of Personhood to guide your practice: comfort, attachment, inclusion, occupation and identity
- Examples are best told as a short story... pause and think of examples in your own work or life about how to best support the personhood of people living with advancing dementia

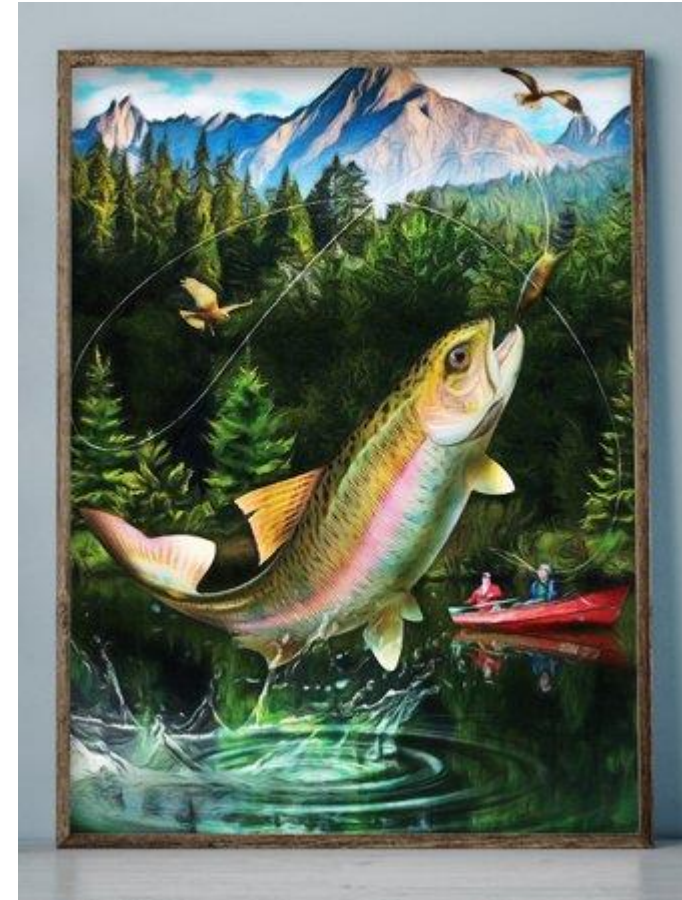
Practice Strategies to Honour and Promote Personhood in Dementia Care

1. Optimize & Preserve Abilities

- Recognize that physical and cognitive abilities will fluctuate over time, between and within days
- Tailor and support care to “just enough” through effective sub-tasking

Dawson, Wells & Kline, 1993

- Use a strengths-based approach to daily living



Story: Jim and his Fish

Practice Strategies to Honour and Promote Personhood in Dementia Care

2. Support Dignity

- Recognize the individual for who they were and for who they are
- Respect their life story and history
- Use of positive not negative language
- Provide behavioural supports (e.g., affirm, stretch, distract)

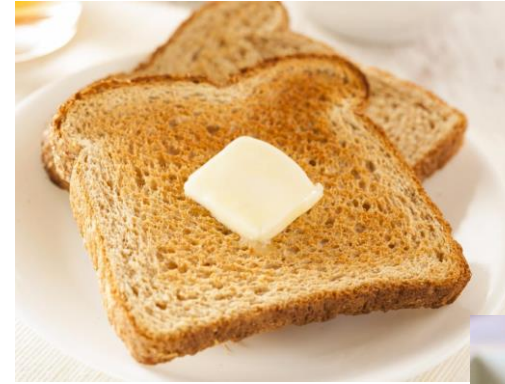


Story: Ben and the Dining Room

Practice Strategies to Honour and Promote Personhood in Dementia Care

3. Honour traditional preferences & habits

- Tailor care to honour known personal preferences, values and life-long patterns- not what currently is
- Examples:
 - Food and Beverage preferences
 - Colour and style choices
 - Social abilities
 - Daily life patterns and routines (e.g., sleep, activity, newspaper)



Anna's Story: "Butter and Toast"; "Tea, no sugar" and "Where is my paper?"

Practice Strategies to Honour and Promote Personhood in Dementia Care

4. Foster Quality of Life

- Seek opportunities for providing meaningful pleasure and fun:
 - Multi-sensory stimulation (taste, touch, sound, smell, sight)
 - Activities (pets, people, kids)
 - Socialization
 - Shared laughter
 - Time and attention - being listened to
 - Sleep
 - Comfort (warm, dry, positioning)



Emma's story: "Soft, so soft..."

Practice Strategies to Honour and Promote Personhood in Dementia Care

5. Lend Voice

- Share & repeat Life Stories
- Engage in & through happy memories (Reminiscence Therapy, photos)
- Sing! (Thompson et al, 2021)



Lisa's Story: The Power of Music

Closing Comments

- Selfhood exists far into advanced dementia
- People living with dementia require others to assist them psychologically and emotionally to maintain their sense of Self
- Personhood is dependent on creating caring relationships that offer recognition, respect and trust
- Person-centred care is fundamental to creating a mutually caring and trusting relationship
- We can access and support Self through the Resident and/or by proxy through their Family/Loved Ones.



**“To love a person is to see all of their magic,
and to remind them of it when they have
forgotten.”**

– Anonymous

Questions, Discussion & Shared Stories

I invite you to unmute and share your...

Questions?

Discussion?

Stories and examples?

... of how to best support and honour Personhood for people who live with advancing dementia...

References

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7. Norberg, Astrid (2019) Sense of Self among Persons with Advanced Dementia (Chapter 13: 205-221) In: Wisniewski, T (editor). *Alzheimer's Disease*. AU, Codon Publications

Wrap Up

- Please fill out our feedback survey- a link has been added into the chat
- A recording of this session and a copy of these slides will be emailed to registrants within the next week
- Please join us for the next Long- Term Care Community of Practice Session:
 - **Title:** Diversity and Inclusion in the Long-Term Care Setting
 - **Guest speakers:** Dr. Amit Arya and Dr. Naheed Dosani
 - **Date/ Time:** September 8th, 2022 from 12-1pm ET

The Palliative Approach in Long Term Care **COMMUNITY OF PRACTICE**

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Advance Care Planning
Planification préalable des soins
CANADA



SPA-LTC
Strengthening a Palliative Approach
in Long-Term Care



Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

Who:

Professionals, patients, caregivers
and other interested individuals

What:

Come together to share experiences
and best practices regarding
Advance Care Planning and
palliative approaches in LTC

Why:

Provide a professional resource to
colleagues

Share tools and resources to
advance best practices across
Canada

Provide a safe space to discuss,
learn and explore different
perspectives

Thank You



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