Community-Based Primary Palliative Care Community of Practice Series 4

Palliative Care for those Living with Dementia

Project ECHO
Palliative Care - Canada
BY
Pallium Canada

Facilitator: Dr. Nadine Gebara
Guest Speakers: Dr. Amit Arya
Date: April 23, 2025

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 and their families.

Stay connected: www.echopalliative.com

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.

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Project ECHO Palliative Care - Canada BY Pallium Canada

LEAP Core

- Interprofessional course that focuses on the essential competencies to provide a palliative care approach.
- Taught by local experts who are experienced palliative care clinicians and educators.
- Delivered online or in-person.
- Ideal for any health care professional (e.g., physician, nurse, pharmacist, social worker, etc.) who provides care for patients with life-threatening and progressive life-limiting illnesses.
- Accredited by the CFPC and Royal College.

Pallium Canada

LEAP CORE

Learn more about the course and topics covered by visiting

www.pallium.ca/course/leap-core

Objectives of this Series

After participating in this series, participants will be able to:

- Augment their primary-level palliative care skills with additional knowledge and expertise related to providing a palliative care approach.
- Connect with and learn from colleagues on how they are providing a palliative care approach.

Overview of Sessions

Session #	Session Title	Date/ Time
Session 1	Pain Management in the Delirious Patient	January 22, 2025 from 12 to 1pm ET
Session 2	Communication: Part 1	February 26, 2025 from 12 to 1pm ET
Session 3	Communication: Part 2	March 27, 2025 from 12 to 1pm ET
Session 4	Palliative Care for those Living with Dementia	April 23, 2025 from 12 to 1pm ET
Session 5	AYA	May 28, 2025 from 12 to 1pm ET
Session 6	Gastrointestinal Symptoms in Palliative Care	June 25, 2025 from 12 to 1pm ET
Session 7	Interventions for symptom management; tubes and drains	July 3, 2025 from 12 to 1pm ET
Session 8	Intimacy and Sexually in Advanced Serious Illness	August 27, 2025 from 12 to 1pm
Session 9	Tissue Donation at End of Life	September 24, 2025 from 12 to 1pm ET
Session 10	Supporting Caregivers	October 29, 2025 from 12 to 1pm ET

Welcome & Reminders

- Please introduce yourself in the chat! Let us know what province you are joining us from, your role and your work setting
- Your microphones are muted. There will be time during this session when you can unmute yourself for questions and discussion.
- You are welcome to use the chat function to ask questions and add comments throughout the session
- This session is being recorded and will be emailed to registrants within the next week.
- Remember not to disclose any Personal Health Information (PHI) during the session
- This 1-credit-per-hour Group Learning program has been certified by the College of Family Physicians of Canada for up to **10 Mainpro+** credits.

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

Facilitator/ Presenter:

- Dr. Nadine Gebara: Nothing to disclose
- Dr. Amit Arya: I receive stipends for leadership roles (North York General Hospital and Kensington Health) and content development (Pallium Canada and the Ontario Centres for Learning, Research and Innovation in Long-Term care)

Disclosure

Mitigating Potential Biases:

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

Introductions

Facilitator:

Dr. Nadine Gebara, MD CCFP- PC
Clinical co-lead of this ECHO series
Palliative Care Physician at Toronto Western Hospital, University Health Network
Family Physician at Gold Standard Health, Annex

Panelists:

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Rev. Jennifer Holtslander, SCP-Associate, MRE, BTh
Spiritual Care Provider

Introductions

Guest Speaker:

Amit Arya, MD CCFP(PC), FCFP
Palliative Care Physician, Ontario
Medical Lead, North York Congregate Access and Support Team
Palliative Care Physician, Freeman Centre for the advancement of Palliative Care
Medical Director, Specialist Palliative Care in Long-Term Care Outreach Program, Kensington Health
Lecturer, Department of Family & Community Medicine, University of Toronto
Assistant Clinical Professor, Division of Palliative Care, Faculty of Health Sciences,
McMaster University

Dr. Amit Arya is a Palliative Care Physician who serves as the Medical Director of two outreach teams providing palliative care services to 10 long-term care homes in Toronto. He holds faculty appointments at the University of Toronto and McMaster University. In 2023, Dr. Arya was invited to advise the federal government on the proposed Safe Long-Term Care Act and also contributed to the development of Canada's National Long-Term Care Standards. In collaboration with Ontario's Centres for Learning, Research and Innovation (CLRI), he has led key educational initiatives focused on equity, diversity, and inclusion in long-term care. Dr. Arya is the recipient of several awards, including the 2024 Award of Excellence in Creative Professional Activity from the University of Toronto and the 2022 Award of Excellence from the College of Family Physicians of Canada. He also co-leads Pallium Canada's Long-Term Care Quality Improvement Community of Practice, which supports Ontario's long-term care homes to integrate equitable, high-quality palliative care through a quality improvement lens.

Palliative Care for those Living with Dementia

Session Learning Objectives

Upon completing the session, participants will be able to:

- Describe how to integrate a palliative approach into the care of people with dementia in a timely and person-centered manner
- Recognize key issues specific to dementia, including advance care planning, pain, BPSD, falls/fractures, dysphagia, and end-of-life care
- Reflect on the importance of equity, diversity, and inclusion (EDI) in supporting people with dementia

Background- Why a palliative care approach is needed in dementia

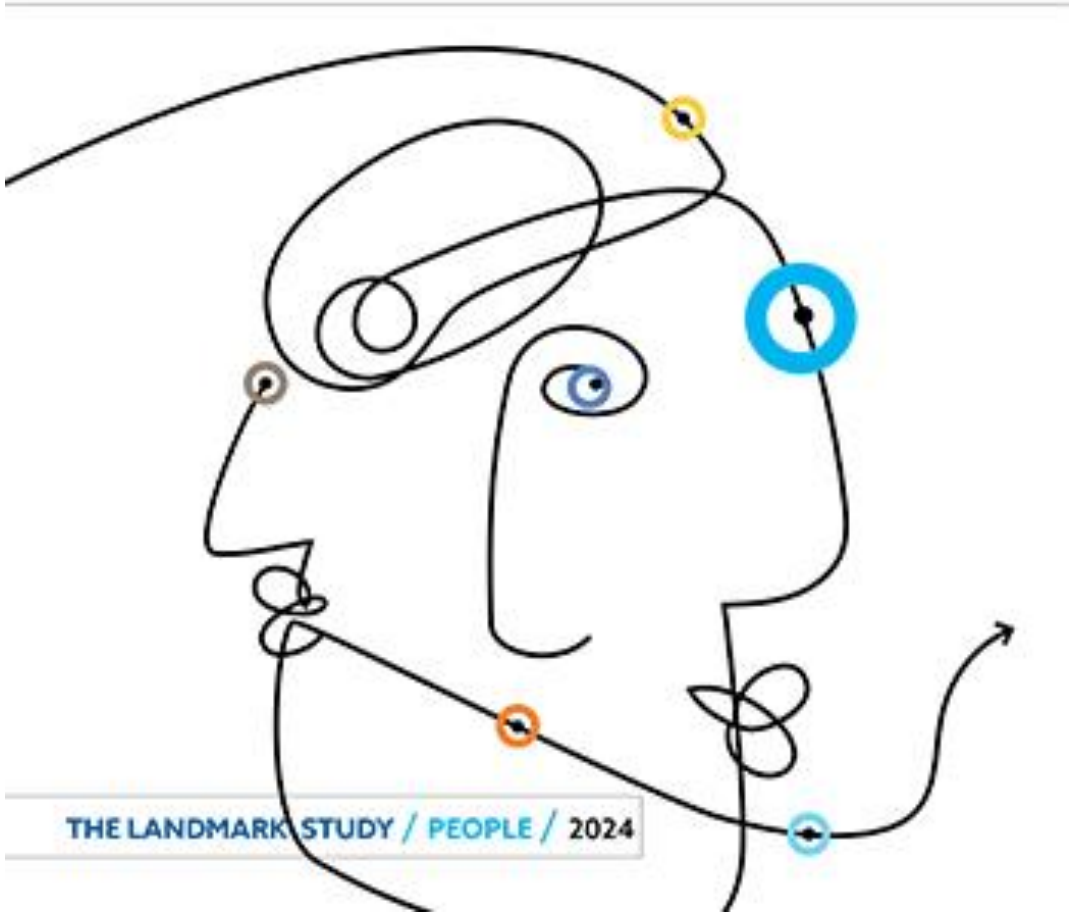
Case: Mr. Chow

- Mr. Chow is an 82-year-old man living with moderate dementia who primarily speaks Mandarin.
  Over the past 6 months, he was admitted to hospital multiple times due to falls.
- Despite ongoing decline, no one initiated advance care planning discussions.
- Palliative care was not considered—because he wasn’t “dying" and his family didn't want to "give up"
- Eventually, Mr. Chow moved into long-term care as “he needed more help.”

Does this case resonate with you?

Why Does Dementia Matter?

- The number of people living with dementia is rapidly increasing
- By 2030, nearly 1 million Canadians will be living with dementia
- Over the next 30 years, this number is projected to increase by 187%
- Dementia disproportionately impacts women—as both people living with the condition and as caregivers
- Dementia is also an equity issue: by 2050, 1 in 4 people with dementia in Canada will be of Asian origin



Yes, dementia IS a life-limiting illness!

Average survival after diagnosis: 4–10 years

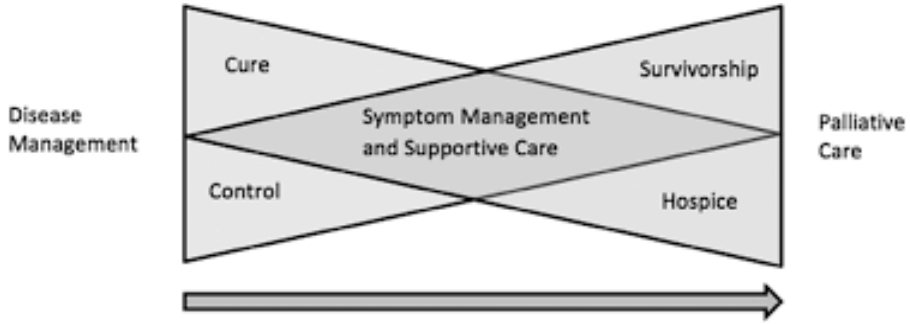
Marked by ongoing functional decline, high symptom burden, and increased caregiver distress

Only 39% of people with dementia are identified as “palliative” in their last year of life

Why should we integrate a palliative care approach early?

What is a palliative approach?

- Not just about end-of-life, can be provided at any stage
- Ongoing care aligned with what matters most
- Holistic, team-based, and integrated into day-to-day care



Advance Care Planning in Dementia

Ms. Daniels

Ms. Daniels, a 88-year-old woman with early dementia, once told her daughter, “I never want to be kept alive on machines.”

She now has moderate dementia and was admitted to hospital with pneumonia. There’s no documented care plan, and her daughter is unsure what to do.

Start with advance care planning

Loss of capacity is inevitable in dementia

Early, ongoing, and meaningful conversations help ensure care is medically appropriate and aligns with the person's values

Advance care planning guides decision-making later, when the person can no longer speak for themselves

Tools to support advance care planning

- Serious Illness Conversation Guide
- Advance Care Planning Canada
- RESPECT tool

Barriers to improving ACP with dementia

Uncertainty about when to start

Fear of taking away hope or upsetting carepartners

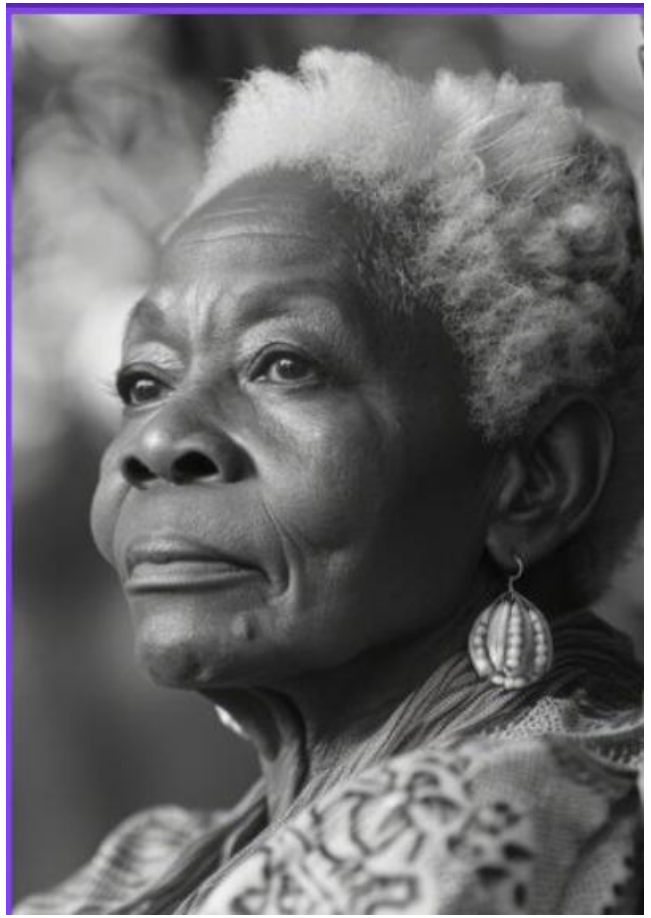
Lack of training or comfort with initiating conversations

BPSD and dementia: Integrating a palliative care approach

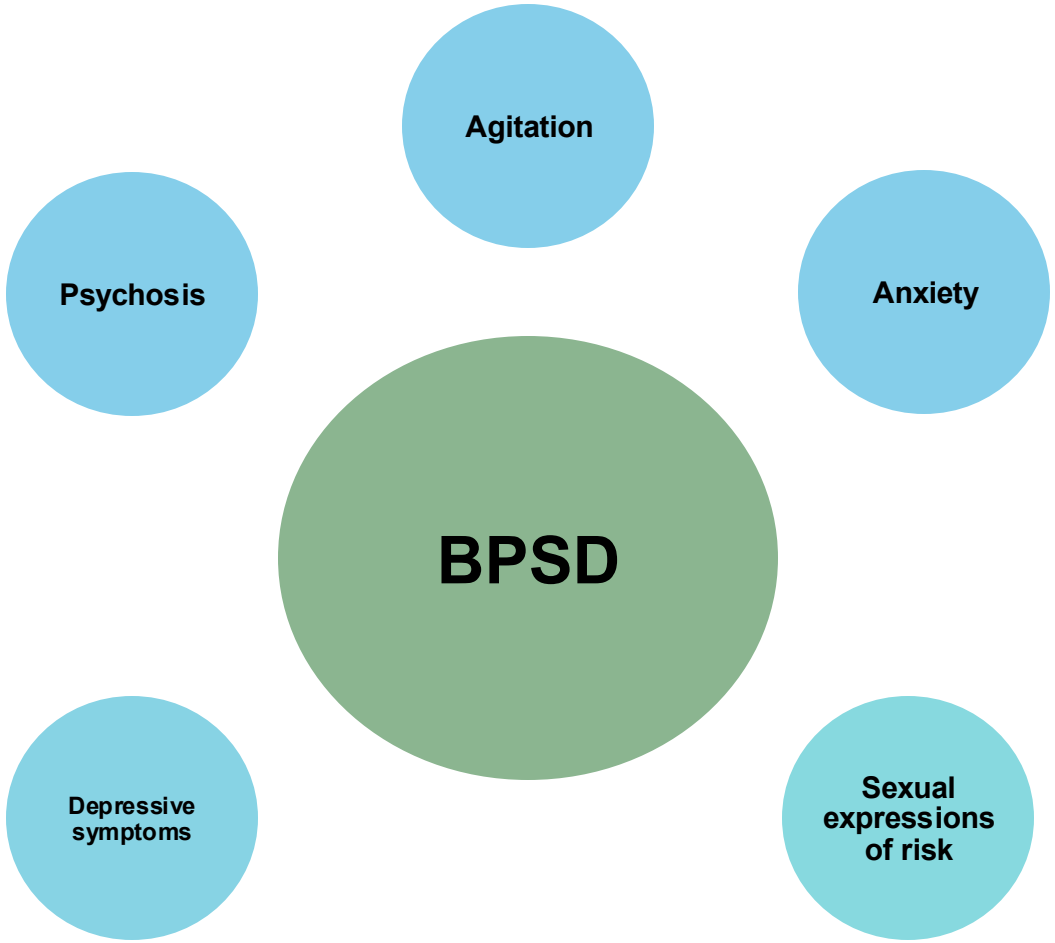
Case: Ms. Adeoye

- Ms. Adeoye is living with dementia and significant BPSD.
- She often punches caregivers when they are trying to assist her.
- Risperidone was started, but her symptoms didn't improve.

What else could be done to manage her expressions of risk?



What is BPSD?


Agitation
Psychosis
Anxiety
BPSD
Depressive symptoms
Sexual expressions of risk

Management of BPSD

Non-Pharmacological Strategies

- Environment: minimize noise, adjust lighting, reduce overstimulation
- Engagement: music, meaningful activities, gentle touch
- Communication: use validation, redirection, calm tone
- Enhanced connection: routines, life story, familiar staff

Pharmacological Strategies

Use only when:

- Symptoms are severe, persistent, and pose a risk of harm
- Non-drug approaches have been tried and were insufficient
- Consent is obtained (resident or SDM) with clear explanation of risks vs. Benefits

Preferred options:

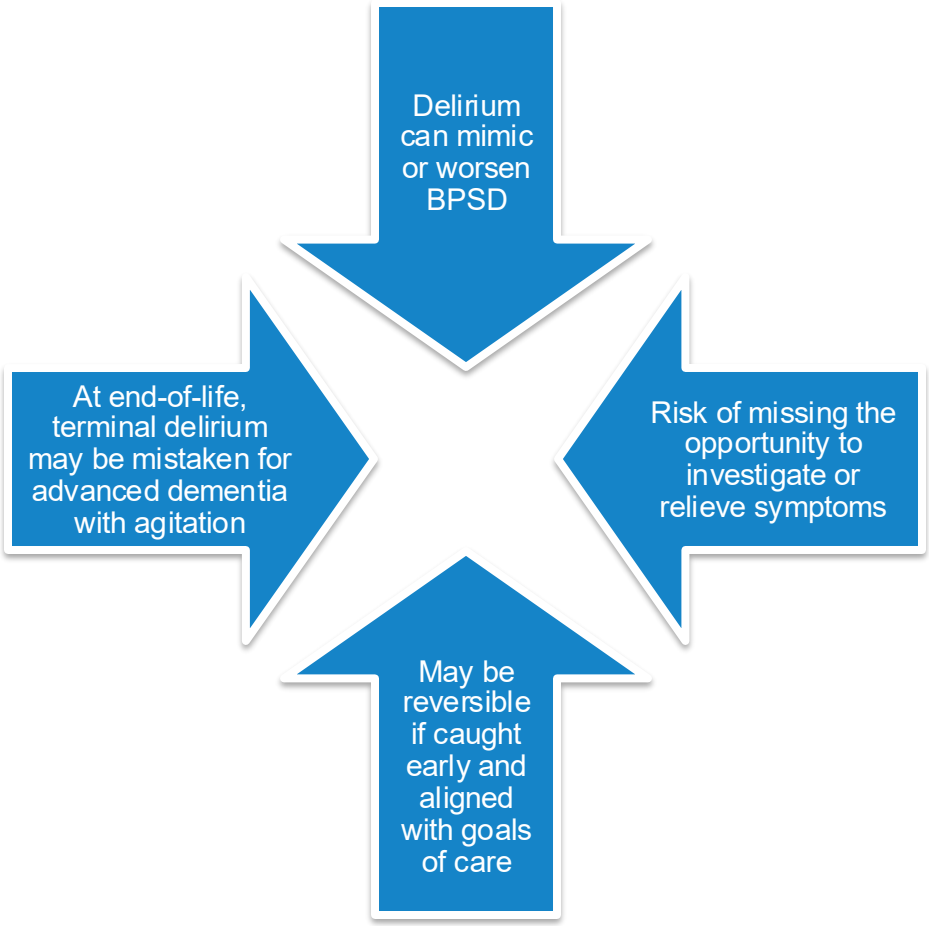
- Citalopram may be helpful in some cases
- Antipsychotics: limited role, significant risks (stroke, mortality), growing concerns about efficacy

Always reassess regularly and document response

Integrate a palliative care approach and plan ahead

- Ensure care aligns with the person's values and goals
- Initiate and revisit advance care planning discussions regularly
- Communicate frequently with the person and their SDM
- Refer to specialized teams (e.g. geriatric psychiatry, palliative care) when appropriate

Delirium or BPSD? Why it matters



Pain and dementia

Case: Ms. Kennedy

Ms. Kennedy, 86, lives with dementia and has been experiencing mood changes. At times, she appears to be anxious and irritable. At other times she is withdrawn. She has a history of osteoarthritis and an old shoulder injury. But other than Acetaminophen, she hasn't been receiving appropriate pain management, due to fear of side effects from medications.

Pain is common, yet under-recognized

- Pain is frequent but often under-recognized and undertreated in dementia
- Up to 80% of people with dementia experience pain
- Limited verbal communication, especially in moderate-to-severe stages, makes assessment of pain more difficult
- Pain may often misinterpreted as agitation or BPSD

Pain assessment tools

PAINAD (Pain Assessment in Advanced Dementia)

Moderate-to-severe dementia; uses behavioural observations

Abbey Pain Scale

For non-verbal residents; combines physical and behavioural cues

Faces Pain Scale – Revised (FPS-R)

For residents who can self-report using visual prompts

Doloplus-2

Combines somatic, psychomotor, and psychosocial indicators

Pain assessment tools

Items*	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation.	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Lowlevel speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial expression	Smiling or inexpressive	Sad. Frightened. Frown.	Facial grimacing.	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	

When to screen for pain

- Routinely (e.g., daily or per visit)
- When a person reports pain or any new symptoms
- When there is a change in mood or emotional state
- With ongoing expressions or any sudden change in personality/behaviour
- When there is a change in health status
- When a resident's usual level of function changes

Pain assessment tips

- Frame questions in the “here and now” (e.g., “Are you in pain right now?”)
- Most residents with mild to moderate cognitive impairment can still self-report pain reliably
- Use concrete, yes/no questions
- Repeat or rephrase if needed
- Use validating statements to build trust and reduce distress
- Ensure communication aids are in place (glasses, hearing aids, lighting)
- Allow enough time for the person to process and respond

Pain management tips

Prioritize	Prioritize non-pharmacological approaches when appropriate
Use	Use acetaminophen as the first-line agent, especially for musculoskeletal pain
Avoid	Avoid long-term use of NSAIDs or COX inhibitors
Use	Use opioids for moderate-to-severe pain, titrated carefully
Consider	Consider adjuvants (e.g., gabapentin) for neuropathic pain or if BPSD is also present
Simplify	Simplify regimens—use long-acting medications when possible to reduce burden and maintain comfort

Falls and dementia

Case: Ms. Wallace

Ms. Wallace, 84, lives in a retirement home and recently had a fall. Labeled a “high falls risk,” she is now kept near the nursing station in a geri-chair and has a bed alarm. She has become increasingly agitated and confused.

Falls=functional decline

- May be an early indicator of disease progression in dementia
- Common cause of ED visits and hospital admissions
- Signals need to revisit goals of care and review a palliative approach

A palliative approach to falls

Falls can be a sentinel event in advanced dementia.

Not all falls are preventable—recurrent falls may signal unmet palliative needs.

Focus on symptom management, comfort, and minimizing distress.

Rethinking falls prevention

1. Shift from “preventing falls at all costs” to a more nuanced approach: falls mitigation
2. Reframe goals to include comfort, dignity, and autonomy
3. Discuss prognosis and care preferences early and often
4. Educate substitute decision makers about the risks and benefits of management of injuries (e.g. surgery for a hip fracture)

Dysphagia and dementia

Case: Mr. Foster

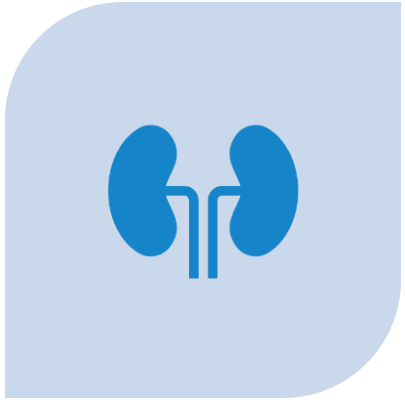
Mr. Foster, 82, lives at home and has advanced dementia. He has been coughing and sounds congested after drinking fluids. Thickened liquids were recommended, but he doesn't prefer them. His family, who live far away, ask PSWs to give him regular water—but the team declines due to risk.

Dysphagia in dementia

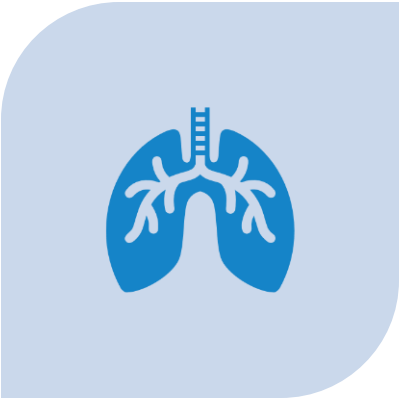
- Common in moderate to advanced stages of dementia
- Increases risk of aspiration and pneumonia
- Can be frightening and emotionally distressing for caregivers and families

Poor evidence for texture modified food & fluids

TEXTURE-MODIFIED DIETS MAY INCREASE RISK OF MALNUTRITION, DEHYDRATION, AND LOWER QUALITY OF LIFE



CONSIDER ALLOWING ACCESS TO PREFERRED FOODS AND FLUIDS THAT THE PERSON ENJOYS AND CAN SAFELY TOLERATE



IF ASPIRATION RISK INCREASES INVOLVE THE IN DEVELOPING A CARE PLAN ALIGNED WITH THE PERSON'S GOALS

Management of dysphagia

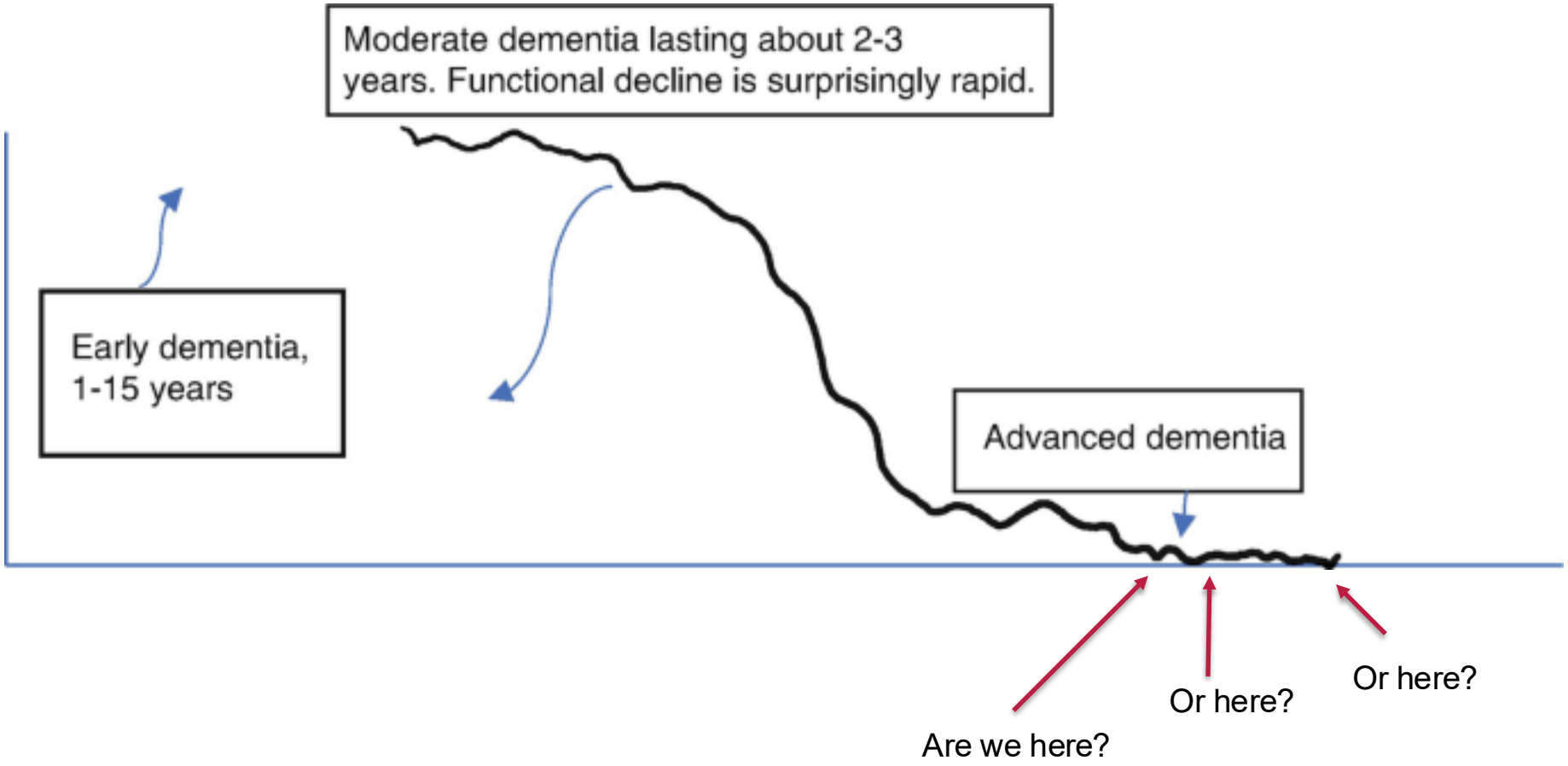
Focus on	Comfort and enjoyment of food
Use	Individualized texture modifications when appropriate
Optimize	Oral hygiene and positioning
Provide	Education and support to all caregivers and family
Explore	Understanding of family and caregivers—consider informational, cultural or religious factors

End-of-life care with dementia

Case: Ms. Schmidt

Ms. Schmidt lives with advanced dementia, has stopped eating for a few days and has increased drowsiness. Her daughter says this has happened twice before, and each time she “bounced back” after a hospital admission. She is unsure what to do now.

Recognizing end-of-life in dementia



Recognizing end-of-life in dementia

- Reduced verbalization, function, swallowing, and weight
- Injuries (e.g., falls, fractures), aspiration, or recurrent infections
- Be prepared for uncertainty and variable recovery
- People may recover after being “sick enough to die”
- Sudden decline and death can follow a period of stability

EDI considerations

Case: Ms. Brown

Ms. Brown, diagnosed with dementia at age 60, lives with her 3 children. As her dementia progresses into the advanced stage, a family conference is arranged where her siblings and other extended family members join virtually from Jamaica. Her children, who feel their mother would want to prioritize comfort, respect the wishes of Ms. Brown's siblings who are very religious and advocate for "doing everything to keep their sister alive."

Viewing dementia through an equity, diversity and inclusion lens

Delayed diagnosis and delayed access to palliative care in marginalized populations

Language barriers impact communication, care planning, and trust

Stigma around dementia may be intensified in some cultural or social contexts

Cultural humility

Ask	Ask, don’t assume
Keep	Keep an open mind and heart
Explore	Explore the person’s religious, spiritual and cultural values

Language and communication

Use	Respect	Understand and support
Use professional interpretation services when needed	Respect requests for non-disclosure or indirect communication	Understand and support collective decision-making when culturally appropriate

Trauma-informed care

Integrate into assessment and management of dementia symptoms

Pay attention to triggers

Honour care preferences and promote a sense of safety

What can clinicians do?

1

Promote equitable access to dementia and palliative care

2

Support culturally appropriate and person-centred care

3

Partner with community organizations to strengthen support networks

Key takeaways

Key takeaways

Dementia is a life-limiting illness that requires a palliative approach

Start early: regular advance care planning and goals of care discussions matter

Integrate a palliative care approach into management of pain, BPSD, falls, dysphagia, and at end-of-life

Prioritize health equity, cultural humility and trauma-informed dementia care

Questions?

Session Wrap Up

- Please fill out our feedback survey, a link has been added into the chat.
- A recording of this session will be emailed to registrants within the next week.
- Join us for our next session on May 28, 2025, from 12-1pm ET for **AYA.**

Thank You

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