Updates & Innovations in Essential Conversations for the Health Care Team

Session Topic: **Frailty and Dementia: Essential Conversations with Families**

Presenter: Dr. Trevor Janz

Thursday April 23, 12:00pm - 1:00pm

Agenda Item	Discussion
Introduction & Key Themes	**<u>Introduction:</u>** • Dr. Trevor Janz: GP with 30 years of experience in emergency, long-term care in Nelson. A strong advocate for interdisciplinary collaboration in patient and family support. **<u>Key Themes</u>** **Palliative Approach Overview** • Focuses on *comfort over cure*, quality of life over quantity. • Involves caring for the *whole person*: physical, emotional, psychological, spiritual, financial needs. • Family is also considered part of the patient unit – their suffering must be addressed too.
Presentation Key points	**Two Essential Conversations** 1. **"Things Are Changing" Conversation** • Initiate when a noticeable decline in function occurs (e.g., falls, incontinence, reduced feeding). • Important to call families proactively rather than reactively. • Builds trust and supports grieving. 2. **"Goals of Care" Conversation** • Topics include CPR, ICU, feeding tubes, surgery, hospital transfers, prolongation of life vs. comfort. • The presenter uses five standard questions to guide these discussions. **Core Elements of the Palliative Model** • Early, frequent, and honest conversations. • Meticulous pain and symptom management (e.g., sleep, mood, bowels, psychosis). • Avoid burdensome interventions (e.g., unnecessary surgeries, hospitalizations, excessive medications). • Shift focus from disease prevention to comfort in final stages of life. **Medication Considerations** • Significant discomfort often comes from the number of medications. • Importance of *deprescribing* medications that no longer align with palliative goals. **Communication Triangle**

- Successful care depends on clear communication between doctors, nurses, and families.
- When all three parties are aligned, patient outcomes and experiences improve.

Tools & Resources

- **Dementia Roadmap** and **Frailty Roadmap**:
    - Educational tools for families to understand disease progression.
    - “Frailty” version uses softer language for those uncomfortable with the term "dementia".

Dementia Trajectory Explained

- **Early Stage**: Loss of complex, instrumental activities (e.g., managing finances, medications).
- **Middle Stage**: Loss of basic daily living skills (e.g., dressing, toileting, eating, walking, talking).
- **Late Stage**: Increased sleep, reduced interest in food/liquids, eventual loss of swallowing, leading to end-of-life.
- Alzheimer's and vascular dementia differ in progression (gradual vs. stepwise decline).

Clinical Signs of Progression

- Increased incontinence, transition to wheelchair use or lifts, change in swallowing or feeding patterns.
- "Sleeping most of the day" and "not waking for meals" are key late-stage indicators.

Signpost Conversations & Dementia Roadmap

- Use the **Dementia Roadmap** to guide care conversations, especially at major changes (“signposts”).
- Ask families specific functional questions:
    - Help with washing/shaving?
    - Bladder control?
    - Falls or walking issues?
    - Interest in food, swallowing issues?
    - Sleeping, pain, bowel function, skin condition, mood?
- Validate and explain symptoms as part of the dementia process.
- Recognize that small factors (infection, poor sleep, dehydration) can worsen function.
- Care plan around safety: hip protectors, foam mats, toileting schedules, etc.
- Involve the full care team: nurses, doctors, family.
- Good palliative care = **meticulous attention** + **building trust**.

Prognostication & Functional Decline

- Focus on **function-based prognostication** (not time-based predictions).
    - E.g., “You may not be able to get up the stairs soon.”
- Communicate uncertainty: “You could live years… or pass away tonight.”
- Be proactive with **advanced care planning conversations**.

Goals of Care Conversation Framework

- Best done early—ideally at first family meeting or care conference.
- Set the tone: "What can we do to improve comfort and quality of life?"
- Cover: medical issues, meds, day-to-day care, activity, food, sleep.
- Save time at the end for "what's important for John and what the future looks like."

Rate of Change as a Key Indicator

- Ask families: "How much has changed in the last 3–6 months?"
- A fast rate of change → more immediate, urgent care planning.
- A slow change → plan for next year with uncertainty in mind.

Assessing Quality of Life

- Ask: **"Are you having any fun?"**
    - Responses give insight into engagement and desire to prolong life.
    - Answers vary from sadness/loneliness to small joys.

Five Key Goals of Care Questions

1. **Life support (CPR, intubation, ventilators):**
    - Most say "no way."
    - Explain futility and harms, especially in frail elders.
2. **Feeding tube after major stroke or loss of swallow:**
    - Usually declined.
    - Avoids years of guilt for families later.
3. **Hip fracture and surgery:**
    - Discuss likelihood of death or delirium post-op.
    - Consider conservative (non-operative) management.
4. **Hospital transfers:**
    - Avoid if possible; care can often be better in LTC facility.
    - Hospitals increase risks (delirium, disorientation).
5. **Prolonging life vs. comfort at end of life:**
    - Would John want life prolonged with aggressive treatment or be kept comfortable and let go?
    - Most choose comfort, and their words should be documented directly.

Documentation & Communication

- Identify and document the **Substitute Decision Maker (SDM)**.
- Ask John (with family present) who should speak for him.
- Record exact phrasing (e.g., "Let me go. I'm ready.") for future reference.
- Having John's voice on record eases family burden and supports palliative decisions.

Group Discussion, Q&A	**Avoiding Bias in Conversations**
	• Everyone has inherent bias, especially with extensive experience.
	• It's important not to influence decisions but rather provide factual information.
	• Families often lack experience with dementia and its progression — they don't know what they're choosing.
	• Clinicians must explain both best- and worst-case scenarios realistically.
	• Encourage families to make informed decisions even if they choose something the clinician wouldn't.
	• Support the family regardless of the choice, including ones that seem unwise.
	Addressing Uncertainty in Prognosis
	• Use analogies to communicate uncertainty (e.g., heart failure — 50/100 people may die each year).
	• Be honest about not knowing exact outcomes, but stress the need for planning.
	• Emphasize that preparation reduces fear, creates confidence, and builds trust.
	Value of Advance Conversations
	• Such conversations offer:
	  ○ Confidence and peace of mind to families.
	  ○ Emotional intimacy and stronger trust between clinicians and families.
	  ○ A "trust bank" that helps when difficult situations arise later.
	• Help families emotionally prepare for future challenges.
	• Conversations aid families in responding more gracefully to crises.
	Practical Language & Phrasing Tips
	• Use empathetic, clear language to reframe medical events in end-of-life:
	  ○ "Your mom isn't dying *because* she has a bladder infection — she has a bladder infection *because* she is dying."
	  ○ Similarly for pneumonia or other common conditions in late-stage dementia.
	• These reframes help families understand natural progression of dementia/frailty.

Resources	• **Video link** • Presenter's email shared for follow-up questions: (trevorjanz@hotmail.com) **Resources** • **Dementia Booklet v26_PRINT.pdf** • **A Frailty Roadmap For Families.pdf**
Closing, Future Sessions	• A part two of the session may be planned based on interest and feedback.