



A Palliative Approach to Supporting Individuals and Families Living With Late and End-Stage Dementia

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Objectives

- Identify when a palliative approach becomes palliative care and hospice care
- Consider when and how to review advance care planning and goals of care
- Understand anticipatory and ambiguous grief
- Review the concerns of families living with late and end stage dementia
- Tips on conversations regarding starvation, the need to feed and comfort care

Do families know that dementia is a terminal, neurodegenerative condition?

- In discussion with Stats Can in 2016 we determined that neurodegenerative conditions were the third leading cause of death in Canada
- When does palliative care begin?

Summary definition of palliative care:

- Hospice palliative care promotes the relief of suffering and the enhancement of quality of life for people living with and or dying from life limiting conditions and the bereaved.
- It's about quality of life until you draw your last breath.
- It's about knowing the survivors will not live with regrets over choices and decisions?

What do you do if you have a headache?

- When does a palliative approach to care begin?
- Do you actually need that entire dose?

Modified View of Hospice Palliative Care

PPS: 60 – 40%

PPS:
≤30%

Diagnosis

Death



Palliative
Approach

Palliative Care

Hospice Palliative
Care

(based on work by L. Librach, F. Ferris, 2004)

When can someone with dementia participate in decision making?

- Speak Up Ontario
- Most persons with dementia are unable to participate in decision making by late middle stage

[What Is Advance Care Planning?](#)[What's Happening in Ontario?](#)[Resource Library](#)[START THE CONVERSATION](#)


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Advance Care Planning is a process of thinking about and sharing your wishes for future health and personal care. It can help you tell others what would be important if you were ill and unable to communicate. [Learn more >](#)



Imagine the person you love most is dying from illness:

- How do you want them to die?
- Where do you want them to die?

- Anticipatory Grief: preparation and completion

- Ambiguous Grief: “I’m a widow waiting to happen.”

Emotion beats Logic

- Goals of care change over time
- Is it possible to restore until death?
- What is realistic?
- Using the Palliative Performance Scale (Victoria Hospice) to note where you are in life's journey
- Your life in 1,000 pages (slow or fast reader)

Prolonging living or prolonging dying?


- Does any moral, religious or legal code teach us that we must prolong life at all cost?
- Are we preparing families to understand the difference?
- Wishful fantasy vs. achievable hope
- Who is suffering?

Late Stage Dementia



Because we can treat must we treat?

- Do we understand the significance of the symptoms? (CASCADE, AMG position paper, Go-Far CPR)
- Do we recognize the progression toward pre-active and active dying with dementia?

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- Does anyone know the patient's expressed thoughts re: treatment, quality of life, etc.
 - Fiero's 4 R's: reflect, reconstruct preferences and values, review and decide as the patient would (Williams-Murphy and Fiero, 2011)

Food and Drink vs. Nutrition and Hydration

- Dysphasia is a final part of the progression of dementia
- “I don’t want him to starve to death”
- “Stop feeding her and don’t give her any liquid or I will sue.”
- Euthanasia, MAiD or comfort?

American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement

- “when eating difficulties arise, feeding tubes are not recommended for older adults with advanced dementia.” (JAGS, 62:1590-1593, 2014)
- What do we expect to happen when we insert a feeding tube?

Prolonging Living and Prolonging Dying

- When we offer food and water to someone who is having trouble with swallowing are we hastening their death (the likelihood of aspiration pneumonia) or prolonging their living (providing calories, nutrition and water)?




Will the provision of food and drink (as tolerated) prolong life in late stage dementia?

- Families need to understand that providing comfort through food and drink is emotional, powerful and has no impact on how long the patient lives

Food and Drink vs. Nutrition and Hydration (helping families understand)

- You've missed your morning alarm and everything has gone wrong all day.
- You haven't had a chance to eat or even to drink a cup of water.
- How do you feel?
- Remember a time you were sick enough to be in bed.
- Did you eat a full meal? Why or why not?




Do people living with illness experience hunger the way they did when they were healthy?

- We have this “need to feed”
- Where does it come from?
- The emotion of food vs. the logic
- Why do you eat?
- Usual responses: “to survive, for energy, for nutrition”
- Then tease out: “for pleasure, comfort, socialization, etc.”



When food is scarce those with the power control the food supply

- Parents have the power and control life, death and nutrition in the early years of a child's life
- If food is a scarce resource what does it mean when food is shared with you?



How do you feel when someone
you love turns away from food?

- How do you feel when they choke when you are the one feeding them?
- Who is suffering?

When patients are no longer able to eat safely:

- Discussions re: risk and benefit of continued feeding
- When they are no longer able to swallow are they going to starve to death?
- Focus of mouth care
- Conscious people who are dying do not drink full glasses of water
- They take enough to moisten their mouths
- Show love through mouth care, massage, prayer, presence

End of life preparation begins at first contact

- Have we done our own preparations for our own deaths?
- Are we comfortable addressing the issues?
- Need to allow time for emotion before logic
- Review significance of symptoms
- Show ways to offer comfort other than food