Panel Presentation: Intersection of Dementia and Assisted Dying

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Discussion today

• Context
• Definition
• Eligibility
• What does it mean for people living with dementia?
• Anecdotal caregiver feedback
• Dementia Society perspective
Context

• 500,000 people living with dementia (PLwD) in Canada...expected to increase to over 900,000 in 2031
• 24,000 PLwD in the Champlain region
• 78,600 new cases per year
• 63% are women
• 9 people diagnosed with dementia in Canada every hour
• Recent study, up to 70% of people with dementia are undiagnosed
• Multiple comorbidities (example, diabetes)
Context continued

• Progressive, irreversible, fatal
• Hereditary for a very, very small percentage; if you have a parent or sibling with late-onset dementia, your chance of developing dementia rises slightly but NOT inevitable
• Lifestyle choices are important
• With the aging of the population, the numbers are increasing
• Long wait lists for long-term care, government is increasing number of beds
• 66% or more of people living in long-term care have dementia
• Federal, National Dementia Strategy
• Ontario, recognition that the health care system needs re-engineering and a commitment to meaningful person-centred, connected care
Definition

- The administering by a physician or nurse practitioner, of a substance, to a person at their request that results in death or,

- The prescribing or providing by a physician or nurse practitioner of a substance to a person, at their request, so that the person may self-administer and in doing so, cause their own death
Eligibility Criteria

• Set federally and includes the following:

- be 18 years or older,
- be capable of making health care decisions,
- have a grievous and irremediable medical condition, which means:
  - the patient has a serious and incurable illness, disease or disability, and
  - the patient is in an advanced state of irreversible decline in capabilities, and
  - the patient is enduring physical or psychological suffering, caused by the medical condition or the state of decline, that is intolerable to the person, and
  - the patient's natural death has become reasonably foreseeable;
- be making a voluntary request;
- provide informed consent to medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.
Implications for People living with dementia

- Age: disease of the elderly but 3-5% of people living with dementia are younger onset.
- Be capable of making health-care decisions (Competent adult able to provide informed consent...this essentially eliminates all people living with dementia as generally mid-late stage not capable)
- You must be able to give informed consent both at the time of your request and immediately before medical assistance in dying is provided (not possible for people with dementia)
- Have a grievous and irremediable disease (advanced stage of serious decline, physical or psychological suffering which is intolerable). Can you predict suffering?
- Natural death is foreseeable (hard to predict this as the dementia path is so varied)
- There are people living with dementia who have other chronic diseases
Canadian Chronic Disease Surveillance System

• In addition to CCDSS data on the burden of diagnosed dementia, including Alzheimer's disease, further information on associated health impacts include:

  ➢ Almost half (48.4%) of Canadians aged 35 years and older with dementia reported having fair or poor general health, and almost one-third (29.7%) having mood disorders.

  ➢ Dementia was associated with high levels of overall disability and specific functional impairments. For example, 58.4% reported impaired mobility, and 37.0% reported moderate or severe pain and discomfort.

  ➢ More than half (56.8%) of Canadians with dementia also reported urinary incontinence, and about one-third (31.7%) reported bowel incontinence.
Power of Attorney for personal care

- A Power of Attorney for Personal Care is a written document in which you give someone the power to make decisions about your personal care should you become unable to make these decisions yourself. Personal care can include your health care, medical treatment, diet, housing, clothing, hygiene, and safety.

- Medical treatment – active vs passive (assisted dying vs. not consenting to a treatment)
Caregiver and Partner Feedback

• “Shoot me”
• Based on what they have experienced with their loved one, they would not want to live but...
• The 24/7 responsibilities and the caregiver suffers
• Religious issues for some
• There is no dignity
• You don’t recognize your family (loved ones), you cannot do anything yourself, what quality of life is there?
• Why can it not be an advanced directive? Why can it not be clear in my written poa for care?
• Is it not humane to end it...
Discussion: What does this mean for people living with dementia and families?

- Legal eligibility criteria have made PLwD generally ineligible (protects vulnerable people).
- Is this reasonable/unreasonable?
- Issue of quality of life, how to measure and is it not subjective?
- Much yet to learn about dementia (neuroplasticity and power of music).
- Some say it is an “unfair” burden for families...families can struggle now with current treatment decisions.
- Is it a slippery slope?
- What about hospice palliative and end of life care?
- What about the extremely small percentage of hereditary dementia?
Reflection by The Dementia Society of Ottawa and Renfrew County

• It is a complex issue.
• This relatively new law reflects societal direction.
• The law requires all eligibility criteria be met for a reason.
• The decision to end one’s life is so personal and irreversible, it should be made by the individual.
• Our desire is for people living with dementia and their families to live well.
• The Dementia Society offers a range of services and supports to help individuals and families achieve their goals from pre-diagnosis to end of life.
• Everyone’s experience with dementia is different and can change; one cannot know what one’s path will be. You cannot predict suffering.
• What impact would appropriate support and palliative care have? Can we change the experience with education, support and investment.
• We know much about risk factors and research is working to find a cure…
Summary

• Complex issue
• Advance medical directives do not apply
• It is difficult to predict suffering
• Reasonable foreseeable death provides you with the right to die if you are on the “verge of death”
• Capacity to make an informed decision essential
• Must consider role of assessors
• Mental health and dementia are areas society struggles with and people with mental health and dementia may be very vulnerable people
• Slippery slope
• Quality of life of PLwD and quality of life of caregiver