# Management of Dementia – The Complex Issues

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# Presenter Disclosure

No relationship or commercial interests to disclose

# Learning Objectives

1. Demonstrate the strategies for managing risk in dementia care
2. Summarize psychiatric features of dementia
3. Examine the impact of caregiver support and planning

# Objectives

- Follow up of previous talk
- Review of dementia diagnosis remotely
- Issues in dementia care
- Unusual dementias

Falls ?

LOW ?

# Virtual Care

- Virtual care is not a type of medicine. Rather, it is a set of tools for delivering care and improving health at a distance
  - synchronously (e.g. video and phone visits)
  - asynchronously (e.g. eVisits, messaging, remote monitoring, and eConsults)

Dord Digit. Med. 4, 6 (2021)

# Diagnosing Dementia
# Cognitive Domains

- Frontal
  - Apathy
    - Are you doing all the planning and organizing
    - What does he do during the day
  - Behaviour
    - Irritable
    - Restless
    - Agitated
  - Executive
    - Complex IADLs (can be captured in functional history)

- Temporal
  - Word finding
    - Has to stop mid sentence (naming nonspecific)
  - Memory
    - Events from the previous day
    - Recent conversations
    - Repeats questions

- Occipital
  - Lost in familiar places
  - Does not recognize family

# Assessment

- Diagnosis
- Investigations
- Pharmacologic management
- Non-pharmacologic
- Complex issues is dementia care

# Dementia Management Issues

- Behavioural features
  - Agitation
  - Apathy
- Advance care planning
  - POA
  - Will
- Caregiver
- Hallucinations

# Complex Dementias

- Syneucleinopathies
  - Lewy body
  - MSA
  - Parkinson's disease
- Frontotemporal dementias
  - Frontal
  - Aphasia

# Agitation in Dementia

- All behaviours are responsive

- Educate caregiver on day one
  - Cognitive domains – frontal functions
  - Communication
    - Don’t confront
    - Don’t contradict
    - Don’t correct
    - Don’t control
  - Empathy
  - The pause/ the cup of tea
  - Not blaming caregiver

# Management of Agitation

- How often
- How long
- Can you distract them
- Safety
- Pharmacologic
  - Anti depressants
  - Anti psychotics
- Be careful of solutions
- Lifeline

# Apathy

- Very common
- Very hard on caregiver
- Very important to recognize and acknowledge

# Depression

- Hard to diagnose
- No antidepressant better

# Financial Management and Planning

- POA
- Representation agreement
  - Rep 9 health care
  - Rep 7 health and basic finances
- Committee / guardianship
- Facility placement act

# Representation 7

- A legal professional is not required for making a Representation Agreement (RA9 or RA7) and no medical assessment is required.

- Capability
  - The traditional approach is based on cognitive ability to understand.
  - An adult may make a Representation 7 Agreement
    - EVEN IF the adult can NOT make a contract.
    - EVEN IF the adult may not appear to cognitively ‘understand’ the RA7.

- Does the adult…
  - communicate a desire to have a representative make, help make, or stop making decisions?
  - demonstrate choices and preferences and can express feelings of approval or disapproval of others?
  - understand that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult?
  - have a relationship with the representative that is characterized by trust?

# Capabilities

- To grant a POA
- Financial capability

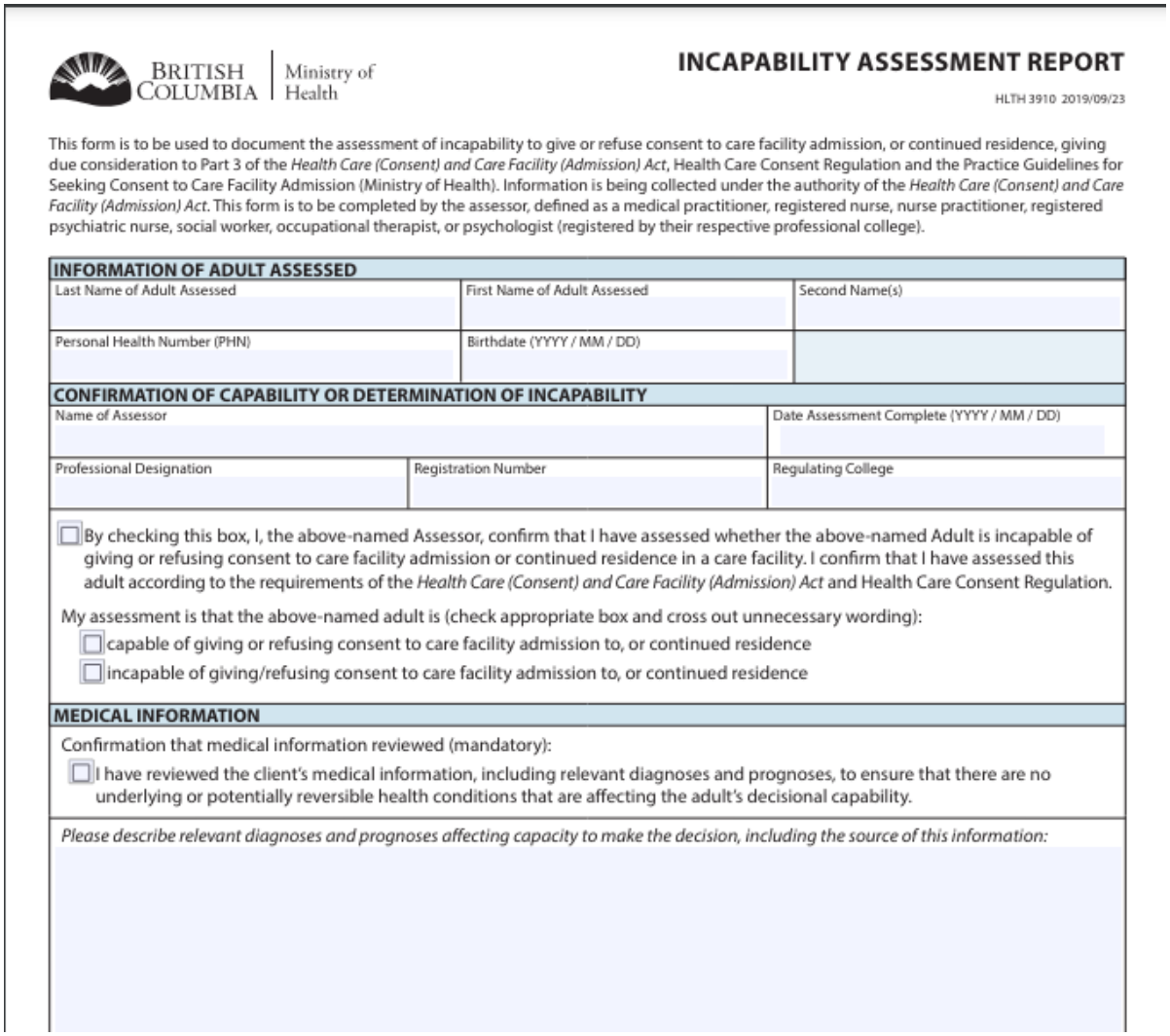
# Scenarios for POA

- POA with trusted person
- No POA no assets – Rep 7
- No POA ,has assets capable and willing – POA
- No POA, has assets, not capable likely need committeeship
- POA and controversy – public guardian and trustee

# Decision-making

- Supportive decision making is the best model even if incapable and has POA
- Need financial capability assessment if making poor decisions /practicality

# Facility Placement



BRITISH COLUMBIA | Ministry of Health

**INCAPABILITY ASSESSMENT REPORT**

HLTH 3910 2019/09/23

This form is to be used to document the assessment of incapability to give or refuse consent to care facility admission, or continued residence, giving due consideration to Part 3 of the *Health Care (Consent) and Care Facility (Admission) Act*, Health Care Consent Regulation and the Practice Guidelines for Seeking Consent to Care Facility Admission (Ministry of Health). Information is being collected under the authority of the *Health Care (Consent) and Care Facility (Admission) Act*. This form is to be completed by the assessor, defined as a medical practitioner, registered nurse, nurse practitioner, registered psychiatric nurse, social worker, occupational therapist, or psychologist (registered by their respective professional college).

**INFORMATION OF ADULT ASSESSED**

| Last Name of Adult Assessed | First Name of Adult Assessed | Second Name(s) |
|---|---|---|
| Personal Health Number (PHN) | Birthdate (YYYY / MM / DD) | |

**CONFIRMATION OF CAPABILITY OR DETERMINATION OF INCAPABILITY**

| Name of Assessor | | Date Assessment Complete (YYYY / MM / DD) |
|---|---|---|
| Professional Designation | Registration Number | Regulating College |

☐ By checking this box, I, the above-named Assessor, confirm that I have assessed whether the above-named Adult is incapable of giving or refusing consent to care facility admission or continued residence in a care facility. I confirm that I have assessed this adult according to the requirements of the *Health Care (Consent) and Care Facility (Admission) Act* and Health Care Consent Regulation.

My assessment is that the above-named adult is (check appropriate box and cross out unnecessary wording):

☐ capable of giving or refusing consent to care facility admission to, or continued residence

☐ incapable of giving/refusing consent to care facility admission to, or continued residence

**MEDICAL INFORMATION**

Confirmation that medical information reviewed (mandatory):

☐ I have reviewed the client's medical information, including relevant diagnoses and prognoses, to ensure that there are no underlying or potentially reversible health conditions that are affecting the adult's decisional capability.

*Please describe relevant diagnoses and prognoses affecting capacity to make the decision, including the source of this information:*

https://www2.gov.bc.ca/assets/gov/health/forms/3910fil.pdf

# Driving

- Start conversation day one
- Fitness to drive

# Assessing Risk

- Capability
- Risk
  - Substantive
  - Evidence of failure
  - Imminent
  - Risk to others
- Intervention
- Risk of intervention
- Informed by
  - Values
  - Goals
  - Best interest vs substitute judgement

# Scenarios

- Mother doesn't take her meds
- Refuses home supports /lock box
- Meds
  - Insulin
  - ASA
- Mother may fall
  - Never has fallen
  - No evident risk of fall
- Mothers house is dirty, refuses help
  - Admit to care

# Caregiver Support and Education

- Alzheimer's Society
- If they could they would
- Sometimes stop the problem-solving doctor mode and just listen
- There are things that have no solution

# End of Life

- It is a terminal condition
- Most common cause of death in US currently
- Prognosis 3-12 years

# Prognosis in Dementia

Susan Mitchell, NEJM 2015

- Followed 323 nursing home with severe dementia for 18 months
- The median survival was 1.3 years
- The most common clinical complications
  - eating problems (86% of patients)
  - febrile episodes (53% of patients)
  - pneumonia (41% of patients)
- If pneumonia/aspiration feeding problems 50% dies with in 6 months

# MAID - Advance Directives

- Advance directives are not binding but do have legal weight but cannot request something that is outside of the law

- Advance request for MAID
  - created in advance of a loss of decision-making capacity,
  - intended to be acted upon under circumstances outlined in the request
  - after the person has lost decisional capacity
  - before a diagnosis of a grievous and irremediable condition.

- 3,500 Canadians >18 years Ipsos I-Say Panel from April 19-25, 2022
  - 85% support an advance request for MAID for individuals with an irremediable diagnosis
  - 77% support an advance request without an irremediable diagnosis

- Special Joint Committee reconstituted with a deadline of February 17, 2023 to report back to Parliament

# Carter Decision & Bill C-14

- In 2015, the Supreme Court of Canada declared in the Carter decision that sections 241(b) and 14 of the Code, which prohibited assisted death, infringed the section 7 Charter right to life, liberty and security of the person.

- A commission set up and in June 2016 Bill C-14 was passed

- Allows individuals
  - 18 or older who have capacity to consent and
  - who have a grievous and irremediable medical condition
  - whose natural death is reasonably foreseeable to access MAID

- Bill C-14 required that three key issues to be addressed
  - MAID for mature minors
  - advance requests for MAID
  - MAID for individuals where a mental disorder is the sole underlying medical condition (MAID MD-SUMC)

# Foreseeable Death

- With new amendments, there are two "tracks" for MAID applications:

    1. "track one" natural death is reasonably foreseeable

    2. "track two" natural death is not reasonably foreseeable

# Current Process

- Make a signed request
- Two assessors
- Track 1
- Waiver of final consent
- Review every 6 months

# Frailty

- Slow
- Fatigued easily
- Poor energy output
- Weak
- Involuntary weight loss

# Fronto temporal Dementias

- Primary progressive aphasia
  - Much better cognition than testing suggests
- Frontal variant
  - Usually apathy
  - Memory may be preserved
  - Diagnosis important since behaviour can alienate family

# Hallucinations

- Lewy body is the classic visual hallucinations
- Other dementias more commonly auditory hallucinations

# Visual hallucinations in dementia and Parkinson's disease: A qualitative exploration of patient and caregiver experiences

Sarah Renouf et. al., 2018

- In early stages of the conditions, insight and cognitive function preserved
  - raising awareness of VHs and treatment options
  - providing opportunities for symptom disclosure
  - reducing stigma
  - Acknowledging VHs and reassuring that they are not harmful
- Cognitive function more impaired
  - shifts to caregiver needs
  - alternative strategies to reassure individuals experiencing VHs
  - recognition that a VH is the individual's reality at the time
  - Attempts to solve problems posed by VH may be more appropriate than challenging their existence at this stage

# Coping strategies for visual hallucinations in Parkinson's disease

Nico J. Diederich MD, 2003

- 36 of 46 Parkinson's disease subjects with hallucinations (78%) used coping strategies
    - cognitive techniques in 69%
    - interactive techniques in 62%
    - visual techniques in 33%

# Summary

- Dementia management encompasses a range of medical ethical and legal issues
- Awareness and discussion of these issues with the caregiver preempts crises and enables a capable caregiver
- Sometimes there are no solutions

Thank you – it’s been fun!

Questions?