Medical Assistance in Dying

The Pharmacist's Perspective

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Presenters' Disclosure

Diane

- I'm getting a stipend for this presentation
- No direct industry funding

Julia

- I'm getting a stipend for this presentation
- No direct industry funding

Learning Objectives

Participants will:

- Know the steps to take if they receive a request for MAiD
- Understand the role of the pharmacist in the provision of MAiD
- Understand the process for eligibility assessment for patients requesting MAiD

MAiD - A case

- Lucy is a 56 year old patient of yours who recently received a diagnosis of ALS
- She presents today with a prescription for Riluzole 50 mg PO BID
- Her current other medications include:
 - Ramipril/HCTZ 10/12.5 PO daily
 - Atorvastatin 20 mg PO daily
 - Vitamin D 1000 units PO daily
 - Calcium 500 mg PO TID-meals
- She has been searching the Internet to seek information on her condition and has seen many reports of ALS patients seeking MAiD
- What should you do?

Definitions

- Medical Assistance in Dying: direct administration or prescribing of medication with intent of terminating a life
- ▶ **Assisted suicide**: the intentional termination of one's life with the assistance of someone else
- Voluntary euthanasia: the intentional termination of the life of a person, by another person, in order to relieve the first person's suffering and done with the individual's consent
- ▶ Palliative care (WHO): an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness
 - Intends neither to hasten or postpone death

Year	Country or State	Voluntary Euthanasia	Assisted suicide
1942	Switzerland	X	✓
1997	Oregon	X	✓
2002	Netherlands Belgium	✓	✓
2008	Washington Montana	X	√
2009	Luxemburg	✓	✓
2012	Finland	X	✓
2013	Vermont	X	✓
2015	California Germany	X	√
2015	Columbia	✓	X
2016	Canada	✓	✓
2016	Colorado	X	✓
2017	District of Columbia	X	✓

Sue Rodriguez asked:

- "Whose body is this? Who owns my life?"
- Request to Court for assisted death denied by small margin 1993
- January 2010
 - ▶ Kay Carter, BC resident, dies in a Swiss Clinic called Dignitas
- ▶ February 2015
 - Carter v. Canada: Supreme Court unanimously strikes down Criminal
 Code prohibitions against assisted dying
- December 2015
 - ▶ Bill 52: Quebec passes An Act Respecting End-of-Life Care
- ▶ June 17, 2016
 - Bill C-14 receives Royal Assent

Prior to Carter v. Canada

- Crime to assist another person in ending their life
 - Person with a grievous and irremediable illness could not seek physician assistance in dying
 - Person faced one of two options:
 - Take their own life prematurely, often by violent or dangerous means
 - 2. Suffer until they die from natural causes
- The Supreme Court of Canada deemed this a cruel choice "depriving claimants of the right to life, liberty and security of the person"

Request for Assisted Dying

Gloria Taylor's statement to the Court:

- "I do not want my life to end violently"
- "I do not want my mode of death to be traumatic for my family members"
- "I want the legal right to die peacefully, at the time of my own choosing, in the embrace of my family and friends"
- "...What I fear is a death that negates, as opposed to concludes, my life. I do not want to die slowly, piece by piece. I do not want to waste away unconscious in a hospital bed. I do not want to die wracked with pain."

Gloria Taylor, an ALS patient was co-claimant with Lee Carter and Hollis Johnson (Carter v. Canada)

- In response to Carter v. Canada
 - Federal government appoints a 3-member external panel to:
 - ▶ Consult with Canadians, medical authorities and other stakeholders
 - Summarize their findings to aid in determining legislative options
 - Territories and Provinces appoint a 9-member group
 - ▶ P/T Expert Advisory Group
 - Examine the issue and **provide recommendations** for legislative options
 - Special Joint Parliamentary Committee
 - Composed of MPs and senators
 - Hold hearings
 - Provide guidance regarding legislative options

MAiD in Canada: P/T Expert Group

- During its deliberations the P/T Expert Advisory Group based its judgement on the following Rights and Duties:
 - ▶ The right to patient autonomy in end-of-life care decisions
 - The rights of freedom of conscience and religion
 - The duty of health care providers to care for patients without abandoning them
 - The right of Canadians to equitable access to health services
 - The right to protection from discrimination as outlined in provincial Human Rights Codes
 - The right to privacy
 - ▶ When rights conflict they must be reconciled

MAiD in Canada: P/T Expert Group

- Final report released November 30, 2015
- 43 Recommendations
 - Available to patients with a grievous and irremediable condition
 - Defined as a very serious illness or disability that cannot be alleviated by means acceptable to the patient
 - Access should not be restricted by arbitrary age-limits but rather consent capacity
 - Ensure access to MAiD: provider-administered and selfadministered
 - Two physicians must assess patient, no pre-defined wait-time
 - MAiD should be available where the patient wants it with no requirement for MD presence for self-administered
 - Conscientious objector be required to refer or direct transfer to another provider

MAiD in Canada: Joint Committee

- Special Joint Parliamentary Committee held 16 meetings
 - ▶ 61 witnesses from various professions and perspectives
 - ▶ 100 written submission
- Recommended:
 - Eligibility be based on definition used in Carter case
 - Should not be limited to those with a "terminal illness"
 - Should not be withheld from patients whose suffering stems from mental illness
 - Could be limited to those 18 years and older initially
 - Advance requests be permitted after diagnosis
 - Written request required, 2 MDs, wait-time determined by MDs
 - Provided by all publicly funded institutions
 - Conscientious objectors provide effective referral
 - Be provided in any appropriate location

MAiD in Canada: Bill C-14

- April 14th, 2016 federal government tabled Bill C-14
- MAiD includes both administering of a substance by a health care provider or self-administration of a prescribed medication
- ▶ Both physicians and nurses practitioners may carry out MAiD; exemption from criminal charges to others who support / are involved in the process
- Persons 18 years and older with a grievous and irremediable medical condition:
 - Serious and incurable illness, disease or disability
 - Advanced state of irreversible decline in capability
 - Causing enduring physical or psychological suffering
 - Natural death reasonably foreseeable

MAiD in Canada: Bill C-14

- Receives Royal Assent June 17th, 2016
- Establishes the right to MAiD for competent adult patients who:
 - Clearly consent to the termination of their life and
 - Have a grievous and irremediable medical condition (including illness, disease or disability) that causes enduring suffering that is intolerable to the individual

MAiD in Canada: definition

- Medical Assistance in Dying (MAiD): A physician or nurse practitioner:
 - Directly administers a substance to a person, at their request, that causes death (voluntary euthanasia); or
 - Prescribes or provides a substance to a person, at their request, so that they may self-administer the substance and in so-doing cause their own death (assisted suicide)
 - Various provinces have chosen to enable one or the other or both of these
 - ▶ In NB both are enabled

- While the majority of Canadians (90%) are supportive of the Carter decision, the idea of physician-assisted dying remains ethically challenging for some
 - ▶ 40% think it should be subject to strict regulations
 - ▶ 70% think conscientious objectors should be required to make referral or enable self-referral
- ▶ 2014 Survey of 5000 Canadian Medical Association members concluded
 - ▶ 45% of respondents favoured legalized MAiD
 - 27% said they would probably participate in it if legalized
- Important values are at stake and potentials for conflict

MAiD – What words do patients use?

Population:

▶ 2157 patients on the palliative care unit of a Paris hospital

Method:

Carers' notes extracted for period from 2010-2011

Results:

- ▶ 195 (9%) patients expressed a wish to die
 - "this has got to stop", "I can't go on",
 - "it's too long", "I can't stand it any more",
 - "kick the bucket", "euthanasia",
 - "I do not want to live any more", "suicide"

MAiD – Who expresses desire?

- ▶ 17% of terminally ill patients express a high desire for hastened death
- Over 50% of patients with AIDS and ALS would consider MAiD
- Nearly 100% of patients with ALS want the option of MAiD available
- Desire for hastened death associated with
 - Lower religiosity
 - Reduced functional status
 - Diagnosis of major depression
 - Poorly controlled symptoms and concerns

MAiD – Reasons for a request

- The right to choose when to end their own life
- Anticipated pain
- Cognitive impairment
- Fear of indignity
- Fear of loss of control
- Concern they may be a physical or financial burden on others

MAiD – How many act on it?

In Oregon:

- I in 6 terminally ill patients will discuss MAiD with family and friends
- ▶ I in 50 will discuss it with their physician
- I in 500 will directly access it
- In 2016, 204 prescriptions were written
 - ▶ 133 patients ingested the medications (included 19 Rx from previous years)
 - > 36 died of other causes
 - No data available for remaining 54 persons
- For the period 1997-2016
 - ▶ Total of 1749 Rx written
 - I 127 persons known to have died from ingestion

MAiD in Oregon who are those pts?

▶ In 2016

- ▶ 96% white, non-Hispanic
- >80% 65 years or older
- >75% well educated (at least some College-level)
- ▶ 79% cancer patients
- > 7% ALS patients
- ▶ 7% Heart disease
- ▶ 1.5% COPD
- ▶ 89% died at home
- ▶ 89% were enrolled in hospice care

Self Administered Procedure			
Pros	Cons		
 •Autonomy •Less "medicalized" •Non invasive •May be done in location and time of choice 	 •Wait too long and unable to self-administer •Greater complication rates •May take a long time to death •Availability of "best" medications for use in Canada (secobarbital, pentobarbital) •Dangerous drug mixture available in the home •Health care provider not always present to handle side effects/complications 		

- For self-administration, the most common prescriptions include:
 - Anti-nauseant (one hour pre-procedure)
 - ▶ Metoclopramide or ondansetron
 - Antianxiety
 - Coma-Inducing Compound
 - Phenobarbital/Chloral hydrate/ Morphine powder combination
 - Suspending liquid/water

MAiD – possible complications

- Most complications have been associated with the oral medications for assisted death
 - In Canada, the oral medications most commonly used in Oregon or Washington (secobarbital and pentobarbital) are not available;
 - Currently most commonly recommended option in Canada is a combination of high dose phenobarbital/chloral hydrate/morphine
 - Most common complications from oral medications:
 - Regurgitation/vomiting
 - ▶ Range of time from ingestion to time of death: I minute to 104 hours
 - ▶ 6 cases reported in the last 17 years of patients regaining consciousness

Voluntary Euthanasia			
Pros	Cons		
 IV prevents problems of emesis IV ensures bioavailability Clinician present if any side effects/complications 	 Less autonomy Requires IV access – more invasive Requires skills for IV access and drug administration 		

- For IV administration, most common prescriptions include:
 - Anxiolytic
 - Midazolam
 - Local anesthetic
 - Lidocaine (or magnesium sulphate)
 - Coma-inducing agent
 - Propofol (or phenobarbital)
 - Neuromuscular blocker
 - Rocuronium (or cisatracurium)

MAiD in Canada - Complications

- For IV administration the most common complication is difficulty accessing an IV site
- Large volume of IV medications that need to be administered – need to use as large a bore needle as possible

MAiD - Back to our case

- Lucy is a 56 year old patient of yours who recently received a diagnosis of ALS
- She presents today with a prescription for Riluzole 50 mg PO BID
- Her current other medications include:
 - Ramipril/HCTZ 10/12.5 PO daily
 - Atorvastatin 20 mg PO daily
 - Vitamin D 1000 units PO daily
 - Calcium 500 mg PO TID-meals
- She has been searching Internet to seek information on her condition and has seen many reports of ALS patients seeking MAiD
- What should you do?

- ▶ June 10th, 2016 New Brunswick's Office of the Attorney General, Public Prosecution Services issued a policy statement that indicates,
- "...no reasonable likelihood of a conviction for charges under 241 (counseling or aiding suicide) for any member of a patient's health care team including ... pharmacists... in discussing physician assisted death (PAD) with a patient as long as those discussions do not constitute the deliberate encouragement or active inducement of a patient to pursue PAD."

- Pharmacists are strongly encouraged to direct patients to their primary care physician/NP or to either the Horizon Health Network or Vitalité Health Network websites or call 811 (Telecare)
 - http://en.horizonnb.ca/media-centre/awarenessinitiatives/medical-assistance-in-dying.aspx
 - http://www.vitalitenb.ca/en/patients/end-life-care/medicalassistance-dying
- Both health regions cooperated in developing patient information resources

- Both Health Regions each have a policy that outlines in detail the steps required for the patient and providers
- Dr.Wildish will walk us through some of these processes and some of the complexities associated with patient evaluation/assessment

- What should be included in a preliminary assessment?
 - Explore the patient's reasons for the request
 - Be aware of your own feelings regarding MAiD
 - Remain non-judgemental
 - What does the patient understand about their illness and prognosis?
 - Are they in a position to make informed choices?
 - Explore all options available to the patient
 - Patient-specific
 - Palliative care
 - Supportive care

MAiD in NB: Conscientious objector

- What if you are a conscientious objector?
- ▶ Bill C-14
 - "… nothing in this section compels an individual to provide or assist in providing medical assistance in dying."

Horizon MAiD policy:

- "In accordance with guidelines established by the NB College of Physicians and Surgeons, the NB Nurses Association or other professional body, a medical practitioner/nurse practitioner, nurse or other health care provider may decline to assist a patient in dying."
- "An attending... will not abandon a patient.... Continues to provide all appropriate care until discharged from this obligation by the patient or due to transfer to another provider."

MAiD in NB: Conscientious objector

- If patient wishes to pursue MAiD and the physician or nurse practitioner does not wish to be involved, they must:
 - Direct the patient to call 811
 - Refer them to a Patient Representative
 - Call the Physician Hotline for referral to a physician who can provide information, assessment and MAiD procedure
 - In Horizon, pharmacists and other health care provided DO
 NOT have direct access to this hotline information

MAiD in NB the Process

- A patient must request in writing
 - Required to start the process
 - ▶ Includes patient statement must be reviewed with the patient
 - Decision to make request must be made by patient
 - If patient unable to physically sign, someone can sign for them
 - Once written request is signed/submitted, I0-day wait period begins

Independent Witnesses

- Independent:
 - Will not benefit under the will of the person making the request
 - Is not a recipient of a financial or material benefit resulting from the person's death
 - Is not the owner, operator of a health care facility, or any facility where the patient is receiving medical treatment or is a resident
 - Is not directly involved in providing health care services or personal care
- Must be at least 18 years of age
- Witness declaration

Eligibility Assessments

- 2 assessments are required from independent physicians or nurse practitioners (one of whom must be a physician)
- Patient must be competent
- Patient must be eligible
- The IO-day wait period can be waived if both assessing practitioners agree that the patient is at risk of not being able to consent to the procedure if they have to wait IO days
 - Because they may lose the cognitive ability to consent
 - They are at risk of profound physical deterioration or death in that time

Eligibility

- ▶ 18 years or older
- Eligible to receive health care funded by a government in Canada
- Has a grievous and irremediable medical condition
 - Serious incurable illness, disease or disability
 - Advanced state of irreversible decline in capacity
 - Enduring physical or psychological suffering that is intolerable and cannot be relieved under conditions acceptable to the patient
 - Natural death has become reasonably foreseeable

Patient Consent

- Patient statement
 - Review with patient
 - Determine method of administration
- Physician/Nurse Practitioner declaration
- Patient must understand that he/she needs to be able to competently verbally consent right up until the procedure starts, even if the Consent Form is signed

- Checklist for Release of Medications
 - Completed by Risk Management
 - Require properly completed:
 - MAiD Patient Request form
 - MAiD Physician/NP Assessment of Eligibility X 2
 - MAiD Patient Consent form
 - If all in order, Risk Management representative forwards completed checklist to hospital pharmacy, which allows time to prepare and release medications to ordering physician/NP

Prescriptions

- Physician-administered vs. self-administered (IV vs Oral)
- Location (home, hospital, nursing home, etc.)
- Timing (Date/Time)
- Discuss with pharmacist (currently only hospital)
- Medications must be given in person from pharmacy to prescribing physician/NP to bring to patient

- The Procedure
 - The Team
 - Administering physician/NP
 - ▶ Pharmacist
 - Nursing
 - □ Ongoing supportive nursing care
 - □ IV access
 - □ Assistance during procedure
 - □ Passing syringes
 - $\hfill\square$ Recording administration of medications for Procedure Checklist

The Procedure

- The setting
 - Who will be present
 - Home
 - □ Nursing support EMP, other
 - ☐ Location/set-up
 - ☐ Funeral home arrangements (by family)
 - Hospital
 - □ Arrange with nurse manager/admin director
 - □ Education for nursing staff
 - □ Requires private room

- Physician/NP-Administered
 - Anxiolytic
 - Midazolam
 - Local Anesthetic
 - Lidocaine (or Magnesium sulphate)
 - Coma Inducing Agent
 - Propofol (or Phenobarbital)
 - Neuromuscular Blocker
 - Rocuronium (or cisatracurium)

- Self-Administered
 - Anti-nauseant
 - Metoclopramide or ondansetron
 - Anti-anxiolytic
 - Coma-Inducing Compound
 - Phenobarbital + Chloral Hydrate + Morphine
 - Suspension vehicle

Post-Procedure

- Completion of Medication Administration Checklist
- Debriefing for anyone directly involved in the procedure
- Return of unused medications and containers to pharmacy
- Completion of Registration of Death
 - Manner of death: Natural
 - Cause of death
 - □ Propofol and Rocuronium toxicity
 - ☐ Medical Assistance in Dying
 - □ Underlying illness

MAiD in Horizon – The First Year

- ▶ 17 completed procedures (all IV)
- Location:
 - ▶ Home 9 (2 in NH)
 - ▶ Hospital 8
 - ▶ 15 SJ, 2 Moncton, I Miramichi
- SJ/Miramichi Numbers:
 - ▶ Gender: M 9; F -6
 - Diagnoses:
 - Cancer 10
 - ALS/MS 3
 - ▶ End-stage heart disease 0
 - ▶ End-stage lung disease I
 - Other I

MAiD in Horizon – The First Year

- Number of Formal Written Requests (SJ) − 21
 - Several people referred but clearly were not eligible so did not make request, or died before they could complete request
 - Others decided they were not really interested
 - 4 people made formal requests but died before eligibility process complete
 - Small number of people have completed eligibility process but are not ready to proceed yet
- Zone specific

MAiD - Back to our case

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 - Atorvastatin 20 mg PO daily
 - Vitamin D 1000 units PO daily
 - Calcium 500 mg PO TID-meals
- She has been searching the Internet to seek information on her condition and has seen many reports of ALS patients seeking MAiD
 - What should you do? Who should she contact?
 - What are the important questions to ask this person?
 - Does she meet the eligibility criteria?

Questions?